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Winterbourne View Review

Good Practice Examples

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Introduction

As part of the Department of Health review into Winterbourne View and how children, young people and adults with learning disability or autism who also have mental health conditions or behave in ways that are often described as challenging, are supported across England, stakeholders reported that although there were many examples of good practice which illustrates the good work that can and is being done in local areas, there is some difficulty in disseminating the good practice. This good practice example document pulls together a number of good practice examples sent in by stakeholders and people who use services across England.

THE MODEL OF CARE

The 1993 report by Jim Mansell, *Services for people with learning disability and challenging behaviour or mental health needs* (updated and revised in 2007) is the key good practice guidance document for those with responsibility for supporting people with learning disabilities or autism and behaviour that challenges. This report emphasises:

- the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
- a focus on personalisation and prevention in social care;
- that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
- that services/support should be provided locally where possible.

Evidence shows that community-based housing enables greater independence, inclusion and choice and that challenging behaviour lessens with the right support. The Association of Supported Living's report *There is an Alternative* (2011) describes how 10 people with learning disabilities and challenging behaviour moved from institutional settings to community services providing better lives and savings of around £900,000 a year in total.

The CQC *Count me in* 2010 census showed only two learning disabled patients on Community Treatment Orders compared to over 3,000 mental health patients – suggesting a greater reliance on in-patient solutions for people with learning disabilities than for other people needing mental health support.

CQC found some people were staying many years in assessment and treatment units, and estimated that in March 2010, at least 660 people were in A&T in Learning Disability wards for more than 6 months.

The good practice case study set out in this chapter shows how the model of care set out in the Mansell reports fits with the new health and care system architecture focusing on key principles, desired outcomes for individuals, and a description of how the model should work in practice.

Key principles

The key principles of high quality services for people with learning disabilities and behaviour which challenges are set out below:

For people

- i. I and my family are at the centre of all support – services designed around me, highly individualised and person-centred.
- ii. My home is in the community – the aim is 100% of people living in the community, supported by local services.
- iii. I am treated as a whole person.
- iv. Where I need additional support, this is provided as locally as possible.

For services:

- v. Services are for all, including those individuals presenting the greatest level of challenge.
- vi. Services follow a life-course approach i.e. planning and intervening early, starting from childhood and including crisis planning.
- vii. Services are provided locally.
- viii. Services focus on improving quality of care and quality of life.
- ix. Services focus on individual dignity and human rights.
- x. Services are provided by skilled workers.
- xi. Services are integrated including good access to physical and mental health services as well as social care.
- xii. Services provide good value for money.
- xiii. Where in-patient services are needed, planning to move back to community services starts from day one of admission.

Outcomes

A high quality service means that people with learning disabilities or autism and behaviour which challenges will be able to say:

- i. I am safe.
- ii. I am treated with compassion, dignity and respect.
- iii. I am involved in decisions about my care
- iv. I am protected from avoidable harm, but also have my own freedom to take risks
- v. I am helped to keep in touch with my family and friends.
- vi. Those around me and looking after me are well supported.
- vii. I am supported to make choices in my daily life.
- viii. I get the right treatment and medication for my condition.
- ix. I get good quality general healthcare.
- x. I am supported to live safely in the community.
- xi. Where I have additional care needs, I get the support I need in the most appropriate setting.
- xii. My care is regularly reviewed to see if I should be moving on.

This is about personalisation, starting with the individual at the centre, living in the community. The first level of support for that individual includes the people, activities and support all people need in their every day lives – family, friends, circles of support, housing, employment and leisure.

Most people with learning disabilities or autism will need more support from a range of sources: their GP or other primary care services, advocacy, a care manager or support worker and could include short breaks. That support may change as needs change, and this will involve assessments of physical or mental health needs or environmental needs (such as loss of a parent, a relationship breakdown, unemployment) to identify what support should be provided.

For people who need further support – including where they have behaviour which challenges – the intensity of support should increase to match need. That should include intensive support services in the community, assessment and treatment services (which could be provided in a safe community setting), and, where appropriate, secure services. But the aim should always be to look to improvement, recovery, and returning a person to their home setting wherever possible.

Responsibility for safety and quality of care depends on all parts of the system working together:

- i. **providers** have a duty of care to each individual they are responsible for, ensuring that services meet their individual needs and putting systems and processes in place to provide effective, efficient and high quality care;
- ii. **commissioners** (NHS and local authorities) are responsible for planning for local needs, purchasing care that meets people's needs and building into contracts clear requirements about the quality and effectiveness of that care;
- iii. **workforce**, including health and care professional and staff who have a duty of care to each individual they are responsible for; and
- iv. **system and professional regulators** who are responsible for assuring the quality of care through the discharge of their duties and functions.

To achieve these outcomes a revised model of care as set out below needs to be delivered.

Model of care – Roles and responsibilities

Good services meeting the needs of everybody must include:

Information

- **Councils, elected councillors, health bodies, voluntary sector, care providers** should provide good quality, transparent, information, advice and advocacy support for individuals, families and carers.

Community based support

- **Councils and health commissioners** should ensure that general services (GPs, hospitals, libraries, leisure centres etc) are user-friendly and accessible to people with learning disabilities/autism so they can access what everyone else can access.
- **Community based mental health services** for this group should offer assertive outreach, 24-hour crisis resolution, a temporary place to go in crisis and general support to deal with the majority of additional support needs at home.
- **Housing** authorities should include a wide range of community housing options – shared, individual, extra care, shared lives scheme, domiciliary care, keyring, respite.
- **Social care commissioners** should ensure the availability of small-scale residential care for those who would benefit from it (eg because they have profound and multiple disabilities).
- **Councils and employment services** should offer support into employment.
- **Councils, voluntary and independent sector providers** should enable a range of daytime activities.
- **Councils** should roll out personal budgets for all those who are eligible for care and support including those with profound and multiple disabilities and/or behaviours seen as challenging.
- Where appropriate, **health commissioners** should fund continuing health care.
- **Health and social care commissioners** should focus on early intervention and preventive support to seek to avoid crises (eg behavioural strategies). Where crises occur, they should have rapid response and crisis support on which they can call quickly.

Commissioning, Assessment and care planning

Health and social care commissioners should develop personalised services that meet people's needs. Key factors include:

- involving individuals - with support where needed – and families at all stages
- planning for the whole life course, from birth to old age, starting with children's services
- developing expertise in challenging behaviour
- developing partnerships and pooling resources to work together on joint planning and support with integrated services – including:
 - multi-disciplinary teams to perform assessments, care planning, care assessment, care management and review,
 - joint commissioning – ideally with pooled budgets, and
 - shared risk management.
- **Health and social care commissioners** should use all available information from joint strategic needs assessments (JSNAs) and local health and wellbeing strategies to commission strategically **for innovation** and to develop person-centred community

based services

- **Health and social care commissioners** should commission personalised services tailored to the needs of individuals, ensuring a focus on improving that individual's health and well-being and agreed outcomes. Progress towards delivering outcomes should be regularly reviewed.
- **Health and social care commissioners** should start to plan from day one of admission to in-patient services for the move back to community.
- **Health and social care commissioners** should ensure close coordination between the commissioning of specialised services including secure services, and other health and care services.
- **Social care bodies** have ongoing responsibility for individuals, even where they are in NHS-funded acute or mental health services, including working with all partners to develop and work towards delivering a discharge plan.
- **Health and social care commissioners should** audit provision to assess which services are good at supporting people with challenging behaviour (the Health Self Assessment Framework is an effective way to monitor outcomes).
- **Health and social care commissioners** should develop effective links with children's services to ensure early planning at transition and joint services. The SEND Green Paper proposal for an integrated health, education and care plan from 0-25 will also help to ensure that children's services are similarly thinking about a young person's transition to adult services at an early stage.

Service Providers

- **All service providers** (community, residential, health, care, housing – public sector, independent sector, voluntary sector) have a duty of care to the individuals for whom they provide services and a legal duty to refer. This includes ensuring that:
 - people are safe and protected from harm,
 - their health and well-being are supported,
 - their care needs are met,
 - people are supported to make decisions about their daily lives,
 - people are supported to maintain friendships and family links.

Providers should:

- provide effective and appropriate leadership, management, mentoring and supervision. Good leadership is essential in setting the culture and values.
- have a whole organisation approach to Positive Behaviour Support training.
- recruit for values and ensure that staff have training for skills – mandatory training which can include training on value bases when working with people with learning disabilities, positive behaviour support, types of communication including non-verbal communication, active support and engaging in meaningful activities and Mental Capacity requirements. Best practice includes involving people with learning disabilities and families in the training.
- operate good clinical governance arrangements.
- monitor quality and safety of care.
- Work with commissioners to promote innovation – new and different ideas, especially for the most challenging.

Assessment and treatment services

- **Health and care commissioners** are responsible for commissioning assessment and treatment services where these are needed. The focus should be on services (which can

be community based) rather than units. Where a person is at risk (or is putting others at risk) in a way that community support cannot help and needs to be moved to a safe place, **commissioners** should focus on this being provided close to home.

- **Health and care commissioners** should look to review any placement in assessment and treatment services regularly, and focus on moving the individual on into more appropriate community based services as soon as it is safe for the individual to do so.
- **Social care services** should be closely involved in decisions to admit to assessment and treatment services.
- All **assessment and treatment services providers** must comply with statutory guidance on the use of physical restraint.

Prisons and secure services

- **Social care services** should work closely with prison and secure services to ensure person centred planning and health action planning and to plan for appropriate provision when people move on from prison or secure services.
- **Offender management processes** should include health screening programmes that identifies an offender's learning disability and any physical and/or mental health issues.

Workforce should demonstrate that they are providing quality care and support which includes:

- personal and professional accountability,
- training in working with people with complex needs and behaviour which challenges,
- developing good communication and involving advocates and families,
- monitoring an individual's progress and reviewing plans, and
- good understanding of the legislative framework and human rights.
- Taking action to report any concerns identified.

System and professional regulators

As a regulator, the Care Quality Commission (CQC) should:

- monitor whether services are meeting essential standards,
- take enforcement action if a provider is not compliant,
- monitor the operation of the Mental Health Act 1983.

Professional regulators such as the Nursing and Midwifery Council (NMC) and General Medical Council (GMC), have a role to play to protect and promote public safety. They do this by:

- setting and maintaining professional standards and
- investigating and taking appropriate action where concerns are raised about registrants, which can include the registrant being removed from the register and where appropriate being referred to the Independent Safeguarding Authority (ISA).

Together the professional regulators have produced a leaflet to help the public to ensure that they receive the care and treatment from professionals who meet the right standards.

PREVENTION

Starting from Childhood

How challenging behaviour is managed in for children and young people with behaviour that challenges has crucial implications for the individual in their later life. Managed well and in an integrated way, and they will be more likely to cope well with the transition to adult services. Difficulties arising in childhood that are not addressed properly or sensitively can have enormous repercussions for the individuals and their families later in life. Good practice at this stage can set the pattern for later life.

Coventry and Warwickshire Partnership NHS Trust¹:

Coventry Children's Community Learning Disability Team set up a process for screening high-risk children in child development units. This process involves working with families in their home/school/respite. The team consists of Community Nurses, Occupational Therapist, SALT, Psychologist and a specialist respite unit for children displaying challenging behaviour. Coventry & Warwickshire Partnership NHS Trust provides funding. A case study on progress is set out below.

Ealing Services for Children with Additional Needs – The Intensive Therapeutic & Short Break Service (ITSBS)

Ealing services for children with additional needs set up "The Intensive Therapeutic & Short Break Service (ITSBS). The service provides a viable model for significantly reducing challenging behaviours and securing home placement stability for a small but significant number of children and young people whose challenging behaviours would otherwise most likely result in a move to residential placements. A detailed outline of the initiative has been provided.

ASL

Members of the Association for Supported Living have come up with examples of community based support solutions for people with learning disabilities who find themselves facing a potential crisis, or who are going through a crisis. The examples show a wide range of critical circumstances that have been sensitively addressed by both commissioners and ASL members, resulting in behaviour that had previously been a cause for concern becoming markedly more positive. The implications of this in quality of life terms are huge, as are the financial implications, as creative and adequately resourced provision is significantly cheaper than its institutional alternative.

¹ The person leading this work is **Dr Pru Allington-Smith**, Consultant Psychiatrist in Learning Disability (Child and Adolescent) working for Coventry and Warwickshire Partnership NHS Trust.

Coventry and Warwickshire Partnership NHS Trust

Case Study – James

James is currently 12 years old and has a severe learning disability, severe autism and severe challenging behaviour. He has been known to the team since he was 6 years old. James lives with his parents, an older and a younger sister. Parents are also heavily involved in the support of their eldest daughter, herself a mother, who has major mental health difficulties.

James became known to the team when his mother became pregnant with her youngest child 5 years ago. At that time major concern was raised about the safety of the unborn child because James was going through a phase of biting young children on the top of the head. He was also aggressive to his parents and existing sisters particularly targeting his 2-year-old niece who was living with the family while her mother was in a psychiatric hospital. James had a lot of stereotypical behaviours and sensory preoccupations. He would spend long periods of time grinding his pelvis against the floor and it was difficult to get him to sit at a table as a result. He would also spit and regurgitate food onto surfaces and then smear the fluid around. He would smear faeces from his pads on a regular basis.

His school placement was in doubt because of the concern over the risk he posed to other vulnerable children. Social services had invoked child protection proceedings around the unborn child. Parents were contemplating splitting up with dad taking James to live elsewhere because of the problems. It was becoming increasingly difficult for mum to care for him on his own while dad was working. The other alternative was for James to go into a residential school which neither parent wanted.

The school referred James to the Children's Community Learning Disability Team. An initial assessment started with the community nurses seeing the parents followed by observations at home and at the school. James and his parents were seen by the Consultant Psychiatrist in the team to look at his overall needs and to introduce Risperidone to reduce James's anxiety levels. Later Carbamazepine was introduced as a mood stabiliser.

The team's Occupational Therapist did a sensory needs assessment and devised a sensory diet for him. Funds were found for sensory equipment for the garden and home. The team's Speech and Language Therapist worked with school and parents to introduce a PECS system for James. Behaviour management guidelines for school and home were devised, introduced and monitored by the community nurses. James's response to a lifelike baby doll was assessed. Training for the school staff was provided by the team. A key worker co-ordinated the team approach and acted as the main point of contact for parents. She also liaised with the psychiatric team providing support for James's sister around her leave home to the parent's house. A place was found in nursery for her daughter.

James's access to a specialist health respite for children with challenging behaviour was increased and when his mother had her baby he had six weeks extra respite returning home in a phased way to ensure that his behaviour

remained settled. During this time there was a marked improvement in his behaviour. He virtually stopped his grinding behaviours and it was possible for school staff to actively engage him. His smearing behaviours greatly reduced. The biting stopped.

The overall outcome was that James remained at home. Increased respite was put in place for the family. School felt confident about managing his behaviours. James remains a challenging young man but five years on is still at home and parents feel they know what to do when there are problems. Parents would like him to remain at home with them until he is eighteen if possible. They know that they can reactivate involvement from the team with a phone call and are seen regularly by the psychiatrist in clinic or in school. Since the initial episode there have been several discreet episodes of involvement from members of the team lasting a few weeks at a time. The team were involved in training the staff of the special school he moved to at eleven.

The team input prevented family breakdown, exclusion from school and a potentially very costly residential placement (estimated costs £160,000 per annum).

Ealing Services for Children with Additional Needs The Intensive Therapeutic & Short Break Service (ITSBS)

Introduction and Aims

The ITSBS continues to be a collaborative initiative between agencies from Ealing Services for Children with Additional Needs (ESCAN), including Clinical Psychology for Children with Disabilities, Ealing Short Breaks Services and Social Services for Children with Disabilities. The aim of the service is to provide a preventative and early intervention approach to support young people with Learning Disabilities who display severe challenging behaviours, and are at imminent risk of residential placement. The ITSBS provides families with short-term intensive interventions (and follow-up support), comprising a carefully tailored package of additional short breaks (if appropriate/needed) and intensive clinical psychology therapy, in order to reduce challenging behaviours and provide a break for the parents/young person, so as to enable the young person to remain within their family home and community settings longer term.

There was a successful pilot of the service in 2008, and a successful first year of service between 2009 and 2010 (see evaluation reports dated December 2008 and August 2010). As a result the ITSBS was extended in 2010 (in terms of increased Clinical Psychology time) so that it could offer the service to a further eight families between 2010 and 2011.

The aim was to offer the ITSBS to eight families in 2010-2011. However, there was a Clinical Psychology vacancy for four months and therefore it was not possible during this time to offer the service to new families. Despite there being a break in service, the ITSBS was still offered to eight families between 2010 and 2011. One of these families had also been seen between 2010 and therefore this was their second Therapeutic Short Break. In addition one of the eight families chose not to engage with the assessment. In addition to offering the service to these eight families, follow up support continued to be provided to the other four families previously seen (between 2008 and 2010) as needed.

Selection of Cases

In 2008 when this service was first piloted, within ESCAN, those most likely to experience a family breakdown and a move to residential school were males aged 11 years plus, with moderate/severe learning disabilities and challenging behaviours. Selection of young people/families to receive the ITSBS continues to be undertaken jointly between the Joint Assistant Directors of ESCAN, Clinical Psychology, Manager of Heller House Short Breaks Service, Head of Children with Disabilities Social Services Team, and Educational Psychology. Referrals have so far been received from Social Services, Community Paediatricians, Psychiatry and Special Schools. Referrers are usually invited to meet with a Clinical Psychologist from the ITSBS before deciding whether to refer a case. This is so that referrals can be thoroughly discussed and so it can be considered whether ITSBS or other services are needed for the young person. Referrals are then considered in the

ITSBS monthly team meeting using the following criteria as a guideline for selection:

- 10+ years old (though the service may occasionally be offered to younger children in exceptional circumstances)
- Diagnosis of Learning Disability and attending a Special School in Ealing
- Already receiving Short Breaks (or about to start receiving)
- Not currently subject to a Child Protection Plan
- Has an allocated Social Worker within the Children with Disabilities Team
- Family and other carers are reporting severe challenging behaviour, high levels of distress and lack of ability to support the young person
- No acute mental health difficulties requiring 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 and have time to work with the ITSBS
- Family and school are both committed and able to consistently implement a behavioural programme at home and school with support from the ITSBS, and able to attend network meetings and Clinical Psychology appointments.

New Cases Seen April 2010-2011

1. Adil²

Adil was 14 years old at the time of referral to the ITSBS in May 2010. He is a British Asian Muslim boy who speaks English and Gujarati. He has a diagnosis of Autism, Learning Disability and Cyclical Mood Disorder and displays Challenging Behaviours. Adil lives with his mother, father and 2 older sisters and attends an Ealing Special School and Heller House short breaks service, though immediately prior to referral to the ITSBS, he had been accommodated temporarily in an out of borough emergency residential placement, as his behaviour became too difficult for his parents, school and short break staff to manage. His family removed him from this residential placement early as they were unhappy with the placement and were keen for Adil to remain in his community settings and avoid the need for permanent residential placement. However, in order to do this it was felt that a clear management plan needed to be put into place across the various settings where Adil is cared for. Adil's Social Worker therefore made a referral to Clinical Psychology within the ITSBS, for an urgent assessment of Challenging Behaviours and to work with the network to develop a clear management plan aiming to prevent Adil's behaviour and mental well-being deteriorating again. In addition a plan was made for responding to any escalation in challenging behaviours or concerns about Adil's mental health.

Assessment

Observations of Adil and interviews with Adil's family and staff team highlighted the following challenging behaviours:

1. Spitting
2. Stripping clothes off
3. Physical aggression e.g. kicking and hitting
4. Destructive behaviours e.g. throwing or breaking objects

² Real names have been replaced with pseudonyms to protect confidentiality

5. Inappropriate sexual behaviours e.g. kissing, touching genitals of staff
6. Setting off fire alarms
7. Refusing to wash or toilet
8. Refusing to go out or move
9. Absconding

Intervention

- A plan was developed by Clinical Psychology detailing the functions of the above behaviours and strategies for preventing and responding to the Challenging Behaviours. This was done in conjunction with all of those caring for Adil – i.e. his parents, Social Services, School, Heller House, and Consultant Psychiatrist.
- Home visits to the family, staff consultation sessions and network meetings were held to implement and review the effectiveness of this plan over a period of 6 months.
- Discussions were held with Social Services and short breaks staff regarding reducing the number of transitions that Adil has to cope with (e.g. reducing the number of different care settings he was attending) as well as liaison with psychiatry regarding medication to support cyclical mood disorder.

Outcome

- Adil continues to live at home and attend his Ealing special school, and family and staff have reported a significant improvement in how they manage challenging behaviour. Adil is no longer at immediate risk of requiring a residential placement.
- Adil's family are now closed to the ITSBS but continue to receive review appointments from the Consultant Psychiatrist.
- On the Carer Outcome Questionnaire³, Adil's family reported that the problems at referral were 'Very severe' and as a result of the intervention the problems 'Improved greatly'. They reported that the meetings with the Clinical Psychologist were 'Very helpful' and felt since these meetings they have 'Greatly improved ability to cope' as carers.
- On the CHI satisfaction questionnaire⁴ Adil's family reported 'Certainly True' for all items e.g. 'Feeling listened to', 'Staff are easy to talk to', 'People have worked together to help my child', 'I feel the staff know how to help', 'If a friend needed help I would recommend this.'

2. Joseph

Joseph was initially referred to the ITSBS in July 2009, and he received a Therapeutic Short Break in September 2009 which was disrupted due to him becoming ill and having to return home. As a result of this and due to the complexity and severity of the challenging behaviour that he displayed, work with Joseph has continued and he received a second Therapeutic Short Break in September 2010 at Heller House.

³ A nine item questionnaire which asks the carer(s) about whether the service they were offered led to changes and whether they now have better ability to cope

⁴ A questionnaire about the carer's opinion of and experience of the service i.e. whether they found the service helpful

Joseph was 11 years old at the time of the original referral to ITSBS. He is a British Mixed Race boy with a diagnosis of Autism, Learning Disability and Hypermobility. Joseph lives with his mother and older brother who has a diagnosis of Asperger Syndrome and attends mainstream sixth form. Joseph attends an Ealing Special School, Heller House short breaks service and the Log Cabin after school club. Joseph's father lives locally and regularly visits Joseph and his brother. Joseph's mother has significant physical health problems and a history of depression. Joseph was referred to the ITSBS by his Consultant Community Paediatrician, Social Worker and Heller House as 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 their family would benefit from this approach.

Assessment

Observations of Joseph and interviews with Joseph's mother and staff team across various settings highlighted the following challenging behaviours:

1. Physical aggression towards staff and family, including smacking, kicking, punching, scratching, pulling hair, and breaking objects and stabbing (with broken plastic, etc).
2. Shouting, swearing, threatening ("I'll stab you") and needing constant attention – clinging to his mother and becoming jealous if she spoke to anyone else.
3. Destructive behaviours – breaking windows, toys and other objects around the family home and short breaks settings. Previously Joseph had tried to light fires but this has stopped since he burnt himself.
4. Other risky behaviours – jumping around in the car or grabbing his mother when she's driving, absconding when out in public places, playing with plug sockets or ripping them from the wall, pouring liquid or urine into electrical sockets.
5. Sleep difficulties – not getting to sleep until 1am and then tired on waking.

Intervention

This included:

- Developing a formulation to support Joseph's family and staff team to understand the above behaviours in the context of Joseph's disability, patterns of learned behaviour, and previous experiences of trauma.
- Supporting and advocating for the family to receive funding for Occupational Therapy adaptations to improve their home environment, making it a safer place for Joseph.
- Providing an extended therapeutic short break at Heller House while adaptations to the home took place.
- Designing and implementing consistent positive behavioural approaches across the various care settings that Joseph was attending and implementing these through regular staff consultation and network meetings.
- Clinical Psychology sessions in the family home and community with Joseph and his mother (and occasionally his brother too) to focus 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 for Joseph's mother to help her reflect on and manage her role in caring for Joseph, 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, and help her understand and come to terms with Joseph's disability.

Outcomes

- Joseph continues to live with his mother and attend his Ealing Special School and Short Breaks settings. Joseph is no longer at imminent risk of requiring a residential placement.
- Joseph's scores on The Developmental Behaviour Checklist (DBC)⁵ and The Parents Three Concerns⁶ indicate a significant improvement in challenging behaviour since he was referred to the service in 2009.

Table 1: Comparison of scores on the DBC and Parents' 3 Concerns Pre and Post Intensive Intervention

Measures	*Pre Intervention scores (09.09)		*Post Intervention scores (04.11)	
<i>DBC Parent</i>	<i>Raw</i>	<i>%ile</i>	<i>Raw</i>	<i>%ile</i>
1. Disruptive/Anti-social behaviour	44	98	26	96
2. Self-Absorbed behaviour	29	94	21	86
3. Communication disturbance	14	96	11	86
4. Anxiety	4	58	4	58
5. Social Relating	8	88	6	78
6. Total Behaviour Problem Score	99	98	83	94
<i>Parents' 2 Concerns</i>				
1. Hurting people or animals	5		3	
2. Destructive – breaking, throwing things	5		3	

***Lower scores indicate lower levels of challenging behaviour/concern.**

- Joseph's mother and staff report that they have observed a significant decrease in challenging behaviours, particularly physical aggression and destructive behaviours. These used to occur pretty constantly throughout the day at home and in short breaks settings, and now occur infrequently – i.e. physical aggression is now rare (<once a month), and destructive behaviours have also decreased.
- Joseph also appears to be calmer and less anxious, and his communication skills and independent living skills have improved.
- Joseph's relationship with his brother has improved, and both his parents have reported feeling more confident and skilled in managing challenging behaviour.

⁵ The DBC is 96-item standardised checklist that is completed by parents or other primary carers reporting behavioural and emotional difficulties in children and young people with intellectual or developmental disability over a six month period.

⁶ This is a measure of the parents' top three concerns with regard to their child and how worried they are about these concerns on a scale of 1-5.

- Joseph's school and short break settings have also reported significant improvements in challenging behaviour and their confidence in caring for Joseph.
- On the Carer Outcome Questionnaire Joseph's mother reported that the problems at referral were 'Very severe' and as a result of the intervention so far the problems have 'Improved moderately'. She reported that the meetings with the Clinical Psychologist are 'Very helpful' and felt since these meetings she has 'Great improved ability to cope' as Joseph's carer.
- On the CHI satisfaction questionnaire Joseph's mother reported 'Certainly True' for all items e.g. 'Feeling listened to', 'Staff are easy to talk to', 'People have worked together to help my child', 'If a friend needed help I would recommend this', 'I feel the people here know how to help the problem I came for.' When asked what she particularly found helpful Joseph's mother said:
"Help managing behaviour and helping me think about changes I could make"
"Being able to share things and look at different ways to deal with problems".
- Recently Joseph's mother also fed back to the service that:
"I used to cry every day and dread Joseph coming home, but now I cry less and sometimes even miss Joseph when he is out, and look forward to him coming home."
- Joseph and his mother continue to be seen by a Clinical Psychologist for weekly sessions.

3. Matthew

Matthew was 11 years old at the time of referral to ITSBS in July 2010. He is a mixed race British boy who lives alone with his mother and has no contact with his father. Matthew has a diagnosis of Autism, ADHD and Learning Disability. He attends an Ealing Special School, Heller House short breaks service, Log Cabin after school club and has carers paid by direct payments. Matthew's mother has some medical and mental health difficulties, and is socially isolated with little support from family or friends. Matthew was referred to the ITSBS by a Clinical Psychologist as there had been a recent escalation in challenging behaviour and Matthew's mother and school were reporting significant difficulties in caring for Matthew.

Assessment

Observations of Matthew and interviews with Matthew's mother and staff team across various settings highlighted the following challenging behaviours:

1. Physical aggression – pushing, hitting, pulling hair and strangling.
2. Shouting, screaming and making vocalisations.
3. Scratching himself when stressed.
4. Risky behaviours –running towards danger (motor bikes, loud noises), running away when outside.
5. Urinating or defecating in inappropriate places and occasionally smearing faeces.
6. Refusing to wear shoes outside
7. Eating liquid soap.

Intervention

This has so far included:

- Developing a psychological formulation to support Matthew's family and staff team to understand the above behaviours in the context of Matthew's disability, patterns of learned behaviour, sensory needs, and his carer's responses to him.
- Supporting and advocating for the family to receive funding for Occupational Therapy adaptations to improve their home environment, making it a safer place for Matthew.
- Providing an extended Therapeutic short break at Heller House.
- Designing and implementing consistent positive behavioural approaches across the various care settings that Matthew is attending and implementing these through regular staff consultation and network meetings.
- Clinical Psychology sessions in the family home with Matthew and his mother to focus on modelling to and supporting Matthew's mother in implementing positive behavioural strategies.
- Psychological support for Matthew's mother to help her reflect on and manage her role in caring for Matthew.
- Supporting Matthew's mother in finding her own personal psychotherapist to support her in addressing her own mental health needs and difficulty in managing interpersonal relationships.
- Ongoing liaison and joint work with Social Services about how to ensure the safety of Matthew while he is living at the family home.

Outcomes

- Matthew continues to live with his mother and attend his Ealing Special School and Short Breaks settings. Matthew's behaviour and staff's ability to support him has improved considerably at school and in short breaks settings. There was also some improvement at home between December 2010 and March 2011. However, these changes have not been sustained at home and as a result Matthew is still at risk of requiring a residential placement, and a large support package continues to be provided to this family. There are also ongoing safeguarding concerns about Matthew's mother's ability to care for him, and therefore the Clinical Psychologist, Social Worker, School and short breaks staff continue to work closely together to monitor the situation and support Matthew.
- Work with Matthew and his family will continue into 2011-2012, and he will have another extended short break while Occupational Therapy adaptations are made to the family home. Therefore, further outcomes for this case will be provided in the 2011-2012 evaluation report.

4. Abdullah

Abdullah was 15 years old at the time of referral to the ITSBS in July 2010. He is a Black African British Muslim boy who lives with his mother, father and 7 siblings. Abdullah has a diagnosis of Autism and Learning Disability. At the time of referral Abdullah attended an Ealing Special School, Heller House short breaks service, Log Cabin after school club and had carers paid by direct payments. Abdullah was referred to the ITSBS by a Consultant Psychiatrist as there had been a recent escalation in challenging behaviours at school, home and Heller House.

Assessment

Observations of Abdullah and interviews with Abdullah's parents and staff team across his various care settings highlighted the following challenging behaviours:

1. Physical aggression – pushing, strangling, hitting and pulling hair.
2. Sexualised behaviours – touching his genitals in public places e.g. at school and Heller House.
3. Non-compliance – refusing to follow instructions at home and school.

Intervention

- Review of short breaks package – focussing on activities where Abdullah is taken out with a carer (where he enjoys and behaves well) versus Heller House – a setting which he found difficult and was felt to be therefore contributing to challenging behaviour as he did not want to attend there.
- Reviewing the plan for preventing and responding to the above Challenging Behaviours that had already previously been developed by Clinical Psychology when Abdullah's family had received support 2 years previously.
- Reaffirming positive behavioural strategies and clear boundaries and instructions that family were already using to manage sexualised behaviour.
- Home visits to the family, staff consultation sessions and network meetings were held to implement and review the effectiveness of this plan over a period of 4 months.

Outcome

- Abdullah continues to live at home with his family and attend his Ealing Special School. He is no longer at imminent risk of requiring a residential placement.
- There has been a reduction in inappropriate sexualised behaviours and physical aggression at home, school and Heller House.
- Staff and family are now consistently responding to sexual behaviours by giving minimal attention and firm boundaries – letting Abdullah know that he can only touch himself in his bedroom or in the bathroom. These boundaries do appear to have had some positive impact, and inappropriate touching has reduced.
- The family were offered ongoing Clinical Psychology support, but they felt able to continue independently following the recommendations that had been made. Therefore Abdullah's care has now been handed back to the Consultant Psychiatrist and Nurse Specialist for less frequent behaviour and medication monitoring.

5. Mark

Mark was 17 years old at the time of referral to ITSBS. He is a White British boy who lives alone with his mother. His father lives locally and he sees him regularly. Mark also has 2 older brothers who live outside of the family home who he has a close relationship with. Mark has a diagnosis of Learning Disability and Epilepsy. At the time of referral he attended the post 16 department of an Ealing Special School and received direct payments for a carer to take him out on trips and a buddying service. Mark was referred to the ITSBS by a Consultant Community Paediatrician following a number of incidents where Mark 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.

Assessment

Observations and interviews with Mark and his mother, his school and his social worker highlighted the following concerns:

1. Self-harm attempts by Mark including attempts to cut himself with sharp objects or strangle himself.
2. Absconding from school/class and barricading himself into areas or wandering around the school.
3. Threats of physical aggression towards others e.g. threatening with a knife, brick or sharp object (but never actually following through on these threats).
4. Non-compliance within the classroom at school.

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 that Mark was transitioning into post 16 at school and adult life.
- Systemic therapy sessions were run weekly by Clinical Psychology with Mark and his mother to focus on exploring their feelings and coping with bereavements, losses and transitions.
- Use of pictures of emotions and situations relevant to Mark's life were used in these sessions until he began to be more able to communicate verbally what he felt worried/upset/angry about.
- Alternative coping strategies were explored and practiced with Mark to support him when he feels upset (to prevent the need for threats or self-harm).
- Joint sessions were held with Clinical Psychology and a drug worker from SAFE Adolescent Team to offer psycho-education about use of drugs and alcohol to Mark.
- Network meetings were held every 6 weeks at school with Clinical Psychology, school staff, Educational Psychologist, 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.

Outcomes

- Mark continues to live his family and has recently chosen to leave school and focus on working part time for his brother's delivery company instead. Mark is no longer at risk of needing a residential or inpatient placement. Mark is now 18 years old so his family are closed to the ITSBS, but he is now accessing Clinical Psychology from the Adult Learning Disability Service.
- Mark's scores on The Developmental Behaviour Checklist (DBC) and The Parents Three Concerns indicate an improvement in challenging behaviour since he was referred to the service in 2010. This is with the exception of anxiety which was higher at the point of discharge. This may be because this was at the time that we were supporting Mark with his transition into adult services and he was worried about this.

Table 2: Comparison of scores on the DBC and Parents' 3 Concerns pre and post intervention for Mark

Measures	*Pre Intervention scores (08.10)		*Post Intervention scores (04.11)	
	Raw	%ile	Raw	%ile
DBC Parent				
1. Disruptive/Anti-social behaviour	38	98	28	96
2. Self-Absorbed behaviour	19	44	8	20
3. Communication disturbance	13	94	11	90
4. Anxiety	9	96	10	98
5. Social Relating	11	94	6	66
6. Total Behaviour Problem Score	99	98	69	84
Parents' 2 Concerns				
1. Expressing himself when scared, sad, etc	5		3	
2. Being able to calm down when agitated and not lash out at himself or others	5		2	

*Lower scores indicate lower levels of challenging behaviour/concern.

- Mark's mother has reported a huge reduction in self-harm behaviours (there have been no incidents of self-harm since 2010). In addition Mark has not displayed physical aggression at home or school since Clinical Psychology began working with him.
- Mark continues to show some destructive behaviours and absconding, but he no longer puts himself or others at risk when displaying these behaviours.
- Overall Mark and his mother report that they are much happier, calmer and more confident again, and Mark's behaviour is more settled at home. Mark is also reported to be more able to communicate his feelings to others and make use of strategies that he knows help him calm down when stressed.
- Mark has really increased his independence and is now in part-time paid employment as a delivery driver's mate, which is reported to be going well.
- On the Carer Outcome Questionnaire Mark's mother reported that the problems at referral were 'fairly severe' and as a result of the intervention the problems 'improved greatly'. She reported that the meetings with the Clinical Psychologist were 'very helpful' and felt since these meetings she had 'great improved ability to cope' as Mark's carer.
- On the CHI satisfaction questionnaire (a questionnaire about the carer's opinion of and experience of the service i.e. whether they found the service helpful) Mark's family reported 'Certainly True' for all items e.g. 'Feeling listened to', 'Staff are easy to talk to', 'People have worked together to help my child', 'If a friend needed help I would recommend this.' Mark's mother also left written feedback on these forms about their experience of the service, which is quoted below:

"Extremely caring, helpful, I could discuss all problems with them with confidence. Could even contact them by phone for reassurance if necessary. Always kind, considerate to one's needs."

“Great service, would recommend it to others who [are] having problems with their children. Always there to listen, advise and take action if necessary.”

“Thank you for your kindness and help over the last year. You both helped [client] 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...”

6. Syed

Syed was 10 years old at the time of referral to ITSBS in November 2010. He is a British Asian Muslim boy who lives with his mother, father and younger brother. Syed has a diagnosis of Autism and Learning Disability. He attends an Ealing Special School, Heller House short breaks service, Log Cabin after school club and has carers paid by direct payments. Syed was referred to the ITSBS by a Clinical Psychologist as there had been a recent escalation in challenging behaviour and Matthew’s mother and school were reporting significant difficulties in caring for Matthew.

Assessment

Observations of Syed and interviews with Syed’s parents and staff team across his various care settings highlighted the following challenging behaviours: Physical aggression – This mainly consists of smacking, kicking, punching, scratching, pinching, pulling hair and stabbing (with broken plastic, etc).

1. Shouting and screaming
2. Destructive behaviours – Syed had broken his parent’s iPod, mobile phone and other technical equipment at home. He had also thrown computers at school.
3. Dropping to the floor – When Syed was being supported by staff at school and by his mother in public
4. Toileting difficulties – Syed would sometimes defecate in inappropriate places such as the litter bin in the school toilets. Syed’s mother had also reported that Syed would choose to pass wind loudly in public places and often find this funny, particularly in the families’ place of worship. Furthermore, Syed’s mother and his teacher at school reported that Syed would often attempt to place his finger up his bottom and smell his finger.
5. Sleep difficulties – According to Syeds mother, he found it difficult to get off to sleep and often became distressed at bedtime, occasionally crying.
6. Throwing food – At both school and home, Syed was throwing plates of food on the floor on quite a regular basis.
7. Obsessive compulsive behaviours – Syed would show signs of distress if he was unable to complete a particular obsession. Obsessions included kissing his mother repeatedly, taking and using other people’s mobile phones, being preoccupied with listening to specific songs on his parents iPhone and obsessing over his parent’s car. Syed would attempt to take his parent’s car keys from them and on one occasion he succeeded by running outside, into the car and started the engine.

Intervention

- A thorough assessment report and formulation were written by Clinical Psychology highlighting the concerns across all settings. A plan for preventing and responding to the above challenging behaviours was also provided.

- Clinical Psychology have also started to work with Educational Psychology in preparing a behavioural intervention focussed on reducing Syed's hitting behaviours, as his aggression is the main concern across settings.
- Clinical Psychology have offered regular visits to home, school and various short break services to aid successful development and implementation of behavioural programme.
- Clinical Psychology and Educational Psychology have collaborated in planning to offer 8 individual sessions with Syed at school to start implementing the behavioural programme and better understand the functions underlying Syed's behaviours.
- Plans have been put into place for Syed to receive a Therapeutic Short Break for 3 weeks at Heller House starting in May 2011.
- Network meetings have been held every 6 weeks at school with Clinical Psychology, school staff, Educational Psychologist, Occupational Therapy and Syed's Mother.
- An Assistant Clinical Psychologist offered Syed's younger brother 18 individual sessions starting in January 2011 which focussed on developing more effective strategies to cope with anxiety within the home environment. A key objective of this work was to help the family in thinking about Syed's brother's role within the family and how he copes with being the brother of a young person with a diagnosis of Learning Disabilities and Autism.

Outcome

- Outcomes for Ali will be reported in the 2011-2012 evaluation report as due to staff vacancy his assessment and intervention planning was only completed in February/March 2011 and therefore most intervention will take place during the new financial year.
- However, in summary currently Ali continues to live at home and his home placement is now stable. He also continues to attend the same school and short breaks services, and again currently all of these placement are stable. Ali is not currently at imminent risk of requiring a residential placement.

Update on previous cases seen (2008-2010)

Please see evaluation reports dated December 2008 and August 2010 for full details of these cases and the support offered. In summary:

James (2008-2009) – family are now closed to the ITSBS. James continues to live with his family and is not in a residential placement. He recently started attending a new day school however which is out of borough. The family report that improvements made during the ITSBS have been sustained – Challenging Behaviour remains significantly reduced in intensity and frequency, family report increased ability to cope, and James presents as happier in mood and has developed his independent living skills including self care and community participation/social inclusion.

Joseph (2009-2011) – see case 2 above. Joseph continues to live with his family who continue to receive support from the ITSBS.

Costs of the Intensive Therapeutic and Short Break Service versus Costs for Residential Placement

Cost comparisons for 2010-2011

Clinical Psychologist Band 8A, 0.5 WTE for 8 months (April-Nov 10) = £20 000
Assistant Psychologist Band 5, 1 WTE for 9 months (July 10-March 11) =£24 000
Cost of 2 x extended short breaks (Jacob and Matthew) = £5022.63 + £3580.26 = £8602.89

Total cost of ITSBS for 7 children 2010-2011 = £52 602.89

Lowest Cost of 1 Residential Placement 2010-2011 = £115 000

Total cost for 7 residential placements 2010-2011 = £805 000⁷

The figures above display the costs for the ITSBS in 2010-2011, in comparison to the costs of the 7 residential placements that were prevented for 2010-2011. The figures show that the total costs for 7 children receiving this service for 1 year was £52 603 in comparison to the average cost of a residential placement for 7 children for 1 year which costs a minimum of £805 000. Costs are only given for one year of a residential placement, but of course these costs would also recur year on year and increase.

Predicted cost comparisons for 2011-2012

Due to the successful outcomes for the cases we have worked with so far, the service will be extended again from 2011-2012. Funding has been agreed for additional short breaks plus four days a week Clinical Psychologist and a full time Assistant Psychologist. With these resources the aim would be to provide intensive work to eight young people in 2011-2012, as well as provide any maintenance work that is needed for previous cases.

The total costs for this will be a maximum of £102 000 per annum broken down as follows:

0.8 Band 7 clinical psychologist	£32 000
Full time Band 5 assistant psychologist	£30 000
4 extended short break support packages ⁸	£40 000 (approx)

This £102 000 will provide intensive work to 8 families and follow up work with previous families (if needed), costing less than the minimum cost of just 1 residential placement for 1 year.

Conclusions

The Intensive Therapeutic and Short Break Service over the last year has continued to prevent a move to residential placement in the short to medium term

⁷ This figure is likely to be much higher as generally young people with Learning Disabilities and Challenging Behaviour will require the more expensive residential placements and these estimates are based on the average cost of a residential placement.

⁸ This is based on the fact that so far only 50% of the families receiving the service have required an extended short break package as well as the Intensive Intervention.

for a small but significant number of young people who were at immediate risk. In addition, all young people previously offered the ITSBS in 2009-2010 have sustained the progress they made and continue not to require residential placements. The evidence obtained thus far, continues to indicate 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.

This model has also received positive feedback from services around the country who have seen it presented at national conferences recently. As a result of this national interest, the ITSBS aims to continue to develop its research base over the next year by collecting more data, building research links, and submitting articles and research papers about the service for publication. Due to the effectiveness of this approach, funding has been continued and extended slightly for 2011-2012 when we plan to offer the service to another 8 families. In addition we aim to provide follow-up support to families who have already received the service as needed to maintain progress and family coping. 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 learning 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 decent quality of life, and this service promotes these values and makes this possible for families for are in considerable need.

Pre-empting, Negotiating and Resolving Crises: Community based alternatives to institutional care

Identifying the factors that can lead to someone exhibiting the signs of challenging behaviour is essential and that entails the professionals involved in their care working closely with individuals and their families. Knowing these circumstances well can lead to the prevention of challenging behaviours and reducing their impact.

Association of Supported Living

Members of the Association for Supported Living were recently asked to come up with examples of community based support solutions for people with learning disabilities, who find themselves facing a potential crisis, or who are going through a crisis. The following are examples of a number of ways in which people were assisted to stay in community based settings – sometimes in the house where they had lived for a long period of time, sometimes in new accommodation where familiar, pre-existing links could be retained. These examples are important because they prevent the damaging effects of being moved away to places often far away from what is familiar. We already know that placements made out of area in times of crisis are a living reminder of what still remains to be done to implement the recommendations of both Mansell reports – 1993 and 2007. Such placements are not only very expensive but they often mean that people acquire a negative label, which is hard to shake off. Their troubled reaction to critical circumstances is often viewed as a problem of personal pathology, rather than one which serves to underline the inadequacy of intervention at the time and the need to re-examine what would help in assisting the person remain near to people or things which afford them some comfort.

The examples show a wide range of critical circumstances that have been sensitively addressed by both commissioners and ASL members, resulting in behaviour that had previously been a cause for concern becoming markedly more positive. The implications of this in quality of life terms are huge, as are the financial implications, as creative and adequately resourced provision is significantly cheaper than its institutional alternative.

There are many issues which emerge from the examples provided, and each example is worth reading in detail. Some of the main things which emerge are:

- There is often time to address a crisis *before* it happens, as all the signs are there of potential problems emerging if nothing is done. This can apply where there is an impending bereavement but, equally, it can apply when someone's behaviour is causing concern to others, such as neighbours and landlords.

- Selection of a trusted, skilled provider and some flexibility around how funding is deployed are key features of good commissioning, as is sensitive reviewing of risk protocols and both perseverance and commitment from front line local authority staff. Both commissioners and families need to have trust in the selected provider.
- Crisis prevention has often been addressed by providers by deploying some interim support in the first instance in order to stabilise the position, whilst working with the person, his/her family, commissioners and other significant local people to develop a longer term support package.
- The availability of good accommodation and support at short notice can be addressed through the use of designated accommodation for such a purpose. The accommodation can be pre-existing or can be sourced quickly through liaison with housing providers, including private sector housing providers. This requires work in advance of crises happening.
- In circumstances of bereavement, a pre-existing arrangement to place the person's accommodation into a Trust can help resolve ongoing problems with benefits.
- A culture of creativity, alongside the availability of a skilled support team, is important in a provider organisation. Difficult problems can often be resolved by careful examination of what's working and not working in critical circumstances and altering practice accordingly to suit the person.
- Providers need to balance skilfully the requirement to provide significant levels of support at short notice with the requirement to ensure staff are well trained and motivated. Use of existing support locations as hubs to source and deploy staff and the availability of an extensive bank of relief staff can help in this regard.

The examples show that where one or more of the factors above exist, chances of supporting people successfully through a crisis are high. They also show that both commissioners and providers have proven themselves capable of helping people find their way through a crisis or helping them avoid an impending one. Some pre-planning by commissioners could help avoid a lot of inappropriate out of area placements. Selecting the provider organisations which have a successful track record in crisis related support, identifying commissioning staff and care managers who have an interest in crisis related work, pre-planning with accommodation providers, having a local behavioural support team and allowing elements of discretion in the flexible use of funding would do much to contribute to securing stability in the lives of people with learning disabilities approaching or experiencing a crisis.

Example 1

What were the circumstances?

“A” is now 51 years old lived with both of his parents all of his life, apart from some stays in a Psychiatric Hospital (when his mental health broke down and he became physically challenging towards his parents). Service user “A” has a diagnosis of a learning disability, paranoid schizophrenia and is also on the autistic spectrum.

“A” received floating support for social trips twice week so that he could get out and about as his parents were elderly and becoming increasingly frail. This support was implemented with the aim that his staff could help him, if one/both parents could no longer care for him. Sadly the service user’s mother died suddenly and the service user was then mostly at home, under his elderly father’s sole care, whilst his father was experiencing major health issues. The relationship between “A” and his father was strained and “A”’s father didn’t really understand his son’s needs. “A”’s mother always took care of “A” and shielded “A” through his personal relationship between him and his father.

Initially, after “A”’s mother’s death, “A”’s father panicked with the caring role that he would need to take and said he felt that his son should be placed in a secure unit, as he couldn’t cope with his behaviours and aggression towards him. The provider organisation’s on call system and floating support staff helped both “A” and his father to calm volatile situations, to ensure that both had a ‘go between’. This meant that they did not have to rely on each other for assistance and that they could deal with issues that arose, through a third party.

“A”’s father subsequently died and “A” now continues to be supported in his own home with his established support team, which enables him to cope at home.

What were the key things that commissioners did in order to make the model work?

The commissioners were open to trying to ensure that the service user had all the opportunities available to him, to receive support in his own home, rather than being taken away and admitted to a secure unit. As he had been physically well and mentally stable for a time, with the correct support and responses to his anxieties, he could remain in the family home.

Commissioners were prepared to listen to those key team members that supported and knew him well and gave the team the opportunity to build a service around him and his remaining family to ensure that tensions were dealt with appropriately by people that “A” and his father had grown to trust. Commissioners also recognised the importance of his current support staff as they had a good understanding of the various family dynamics occurring. As “A” has paranoid schizophrenic who is on the autistic spectrum, it would be very difficult for “A” to move home and be introduced to numerous new support staff, as he would not be able cope with the changes involved which could result in him being physically aggressive.

What were the features of the support that led to it being successful?

- Consistent staffing
- 24hr on call service
- Support and trust of commissioners to lead service
- Trust of family
- Trust of service user
- Opportunity to develop service around a person, not a service that a person has to fit into
- Circle of support involvement and commitment to work as a team to make the situation work
- Care managers understanding alternatives to locking people away and being supportive around risk management
- Organisation able to ensure that staff are adequately trained in working with people with very complex needs and maintaining safe, lone working arrangements around behaviours that may challenge a service

What has been the outcome for the person and how much did/does the support arrangement cost?

“A” continues to live independently with assistance from his floating support staff. He continues to be happy living in his family home and has coped very well with his change from being cared for - to caring for himself and advocating for his own needs. He gets some natural support from his neighbours which would not have happened if he moved into a residential unit. “A” has learnt to cope with emergencies alone and has gained confidence in managing *ad hoc* situations that occur in his home.

The outcome for commissioners is that they now have a service that is designed around an individual (that costs under £320 per week), as opposed to a restricted placement in a secure unit (that could cost around £1,500 per week).

Were there any housing aspects to the provision of this support that need mentioning?

“A” inherited the family home from his parents and he can now remain living in the family home until he dies, if that is what he wishes to do. His parents were forward thinkers and pre-planned their affairs so that on their joint deaths, the house was put into a Trust for their son and this negated any complications around income and benefits that he is entitled to.

Example 2

What were the circumstances?

One individual we supported in a four person service for individuals with ASD and behaviour support issues who went into mental health crisis. The individual had successfully moved from a treatment and assessment unit, where he had been ‘living’ for 15 years into the supported living service. The service developed robust support practices and risk assessments to successfully support the individual with

his enduring mental health issue. However, what became apparent was that a flat of his own would be beneficial. Behaviours escalated related to the dynamics of living with others, in particular one other individual. The clinical psychiatrist wanted to re-admit him to a treatment and assessment unit.

What were the key things that commissioners did in order to make the model work?

Firstly, there needed to be an acceptance that the model of support needed to change.

This was not about blaming the service for failure. In fact the service was a success. We had to make a strong case that the issue was one of service model and compatibility with the individual(s) he was living with and a clear argument that he should continue to be supported in the community and demonstrate how risks were to be managed. From a commissioning point they needed to stick with us. We produced evidence and reports that were able to challenge the assertion that re-admittance was the best option. We were successful; the only issue was that property-wise he had to move onto another provider.

What were the features of the support that led to it being successful?

- Collating of evidence that given the right support and service model the individual could continue to live successfully in the community
- Service able to demonstrate that they could support the individual in the interim period, whilst a new service was designed/ sought
- Commitment from a service to support the needs of the individual and appropriately managing risks in the interim period between services
- Commitment from family. The individual was able to spend more time at his parent's home, with 'outreach' support from the service.
- Commissioner accepting the case for continued support in the community and sourcing an alternative service.

What has been the outcome for the person and how much did/does the support arrangement cost?

No change in costs of the service – just the service model. Had he moved back into the Treatment and Assessment unit, the costs would have been much higher. The difficulty is that when costs move between Social Services and Health the true picture of actual costs is lost. It shifts from one budget to another and, therefore, comparison of real costs is not made.

The individual is now living in his own flat, so greater independence and control and able to receive support in a model that best meets his needs.

Were there any housing aspects to the provision of this support that need mentioning?

Access to housing was a problem. As stated it would have been better to continue to be supported by us as a satellite service but the outcome was still successful

and he did stay in the local area close to his family. If housing had been available, it would have been even better! Available housing is often a problem when individuals need to move on. The issue is that a service goes into crisis and timescales are too short to get on any housing lists, etc. What is needed is joined-up working around housing stock, particularly property that may be suitable for individuals with support needs around behaviours that may challenge.

Example 3

What were the circumstances?

SK is a young man with autism and severe learning disability who lived at home with his parents. He had 8 weeks per year respite provision in a residential facility in addition to 30 hours per week support from a provider organisation.

SK presented various behavioural challenges, including aggression and violence towards his parents. A point arrived when SK's behaviours again escalated to where his parents were frightened and could not cope with the challenges being presented to them. The respite facility refused to accommodate SK because his behaviours were frightening and alarming to other residents and they did not have the necessary staffing resources to effectively and safely support him. The parents had approached Social Work on several occasions to request some respite and had been pressing for SK to have his own tenancy with a 24 hour supported living service.

In desperation, the parents took SK to the social work base at the learning disability resource centre which includes a NHS assessment and treatment centre. The parents demanded that SK be admitted and stated that they could no longer care for him in their home because their own health was deteriorating rapidly.

What were the key things that commissioners did in order to make the model work?

SK was immediately admitted to the learning disability assessment and treatment unit; initially for a period of 4 weeks. The provider continued to support SK inside and outside of the unit in order to maintain continuity for him and to ensure that he received the one to one care that he was used to. The provider's staff and nursing staff collaborated closely to ensure that everyone was working in the same consistent way with SK. There was regular communication, sometimes on a daily basis, between the provider's service manager, the social work care manager and the designated nursing staff member. This ensured that everyone was aware of developments and ensured that goals were adjusted and updated frequently with this being effectively communicated to all the relevant people.

An immediate application for housing was made and a key element of this was that the house needed to be within the same area that he had lived all his life and close to his parents' home.

An assessment of SK's behaviours was carried out with input from a consultant psychiatrist, a consultant psychologist, social work, nursing staff, dietician, speech and language therapist, occupational therapist and the provider. Medication was

reviewed and a new regime commenced. There was a focus upon supporting SK to maintain his daily living skills and embedding a routine and structure to his daily life. Regular review meetings were held every 4 weeks and included all the professionals involved; a housing officer, an advocate and his parents. Planning for the future was the priority, partly because the assessment unit has only 12 beds for the whole region and was never intended to provide ongoing care. Eventually, after 4 months, a suitable house was allocated and the provider was asked to provide 24-hour support. The phase of introducing SK to his new home began with visits taking place in a planned way for him to be involved in the house being decorated and furnished. SK's parents were also closely involved with this and their presence in the new house reassured SK and helped him to understand that it would become his home.

What were the features of the support that led to it being successful?

- Immediate response from medical professionals;
- Immediate response from social workers;
- Continuity of care provided by the provider;
- Involvement of parents;
- Creating a multi-disciplinary team of professionals working towards very clear
- Common goals;
- Effective (regular and frequent) communication amongst multi-disciplinary team.

What has been the outcome for the person and how much did/does the support arrangement cost?

SK has now been residing in his own home for around 6 months; he is settled and happy. The provider is looking towards supporting SK to undertake a varied range of activities in an effort to establish a structure to his daily life. His parents visit regularly and frequently and have close involvement in all aspects of SK's life.

SK's support increased from 30 hours per week to 112 hours + 7 sleep-overs. The total cost per week is £1,895.74; this reflects increased costs of £1,458.34 per week. There have been savings for the local authority related to the respite provision which is no longer needed.

Were there any housing aspects to the provision of this support that need mentioning?

A local authority housing application was made; the house needed to be in a specific area that was familiar to SK. This is because, due to his autism, he finds changes distressing a difficult to manage; this can result in an escalation of behavioural challenges which we wished to minimise for safety reasons. It was also important to SK's parents that they were able to visit their son on a daily basis and retain a close involvement in his life. Much of the decorating and furnishing of the house was completed by the parents and support workers. This ensured that SK was involved at all stages and he dealt with the changes on a gradual basis rather than a complete change being presented to him.

Personalisation

Personalisation is at the heart of transforming care and support for people with learning disabilities or autism and behaviour which challenges. Sadly, the CQC inspections identified real concerns about the quality of person-centred planning for people in some units. Involvement of people in developing their care plan was limited. Care plans were not person-centred and were unable to inform the delivery of care in a way that met individual needs and ensured patient welfare and safety.

A key part of personalisation is about increasing user choice and control. This means starting with the individual at the centre. The case studies below highlight how delivery of personalised care can make an enormous difference to people's experience and lead to fulfilling lives.

Summary

Pineroft⁹:

Pineroft is a specialist residential home run by the National Autistic Society in Alveston, a small village on the outskirts of Bristol. The service can support up to four people with Asperger syndrome or high-functioning autism who may be on a conditional discharge or community treatment order under the Mental Health Act 1983. Each person supported at Pineroft has their own personal care plan and all staff receive specific training to meet individual needs.

Dimensions:

Dimensions is committed to personalisation and its core aim is to support people to have real choice and control over their lives which means supporting them to become much more involved in making their own choices and decisions – such as choosing who supports them, when and how. But a service can only be 'personal' if people have control over the funding to pay for support of their own choosing. In essence this means creating Individual Service Funds. Dimensions has begun to develop ways to implement Individual Service Funds within residential services that operate under traditional block contract arrangements. Starting with a traditional care home, it enabled the six people supported to be in control of their own budget, choose their own activities, support staff and staff rotas. This involved determining how to allocate the existing funding to individuals in a fair and equitable way to reflect their individual needs, and devising a framework that would identify an individual allocation for each person supported; core support and shared costs; and a budget that people could control ('in my personal control'). The people who live in the service now have support plans that look very different from previously, based on how they choose to spend their personal budget and who supports them with the activities they have chosen.

Pinecroft

Positioned near local amenities and bus routes, the house is situated three miles from a major shopping complex and is within easy reach of Bristol city centre. Each individual has their own bedroom and in addition there are shared rooms including two lounge areas, a kitchen diner, a light and airy conservatory and a large garden. Individuals are involved in all decisions regarding their home from decorating and food choices to recruitment of staff. A house meeting is held every two weeks so that residents can discuss what they want to do and plan future events, such as Easter or Halloween.

Each person living at Pinecroft has complex needs, and they often have additional mental health diagnoses such as schizophrenia or psychosis. They also often have other health issues, for example two of the residents have epilepsy, one has diabetes, and another has been supported through skin cancer.

All individuals are assessed before being accepted into Pinecroft. The referral system includes several meetings with the person and their family, a social worker, and Pinecroft staff in order to gather information about the individual, to write a risk assessment, and also to develop timetables and care plans. Before visiting Pinecroft for the first time, photos of the service and staff are sent to the individual so that they will be familiar with the surroundings when they arrive.

A compatibility assessment is then completed to ensure that the individual will be compatible with others who live there. Planning for a new individual to move in also includes looking at the need for psychiatric support and whether extra funding is needed for psychology or any other specialist support. Once the service design has been approved, a transition plan will then be put in place.

A person-centred plan is developed with each individual and a structured timetable is produced around this, taking account of the individual's needs and aspirations and access to community-based activities. These are reviewed and evaluated monthly with the individual and their planning team. Further external support comes from consultant psychiatrists and clinical psychologists as required, all of whom have extensive knowledge and experience of Asperger syndrome and challenging behaviour.

All staff at Pinecroft undertake autism and person-centred planning training and are experienced in working with people on the spectrum. As part of the required induction, all members of staff receive comprehensive training, including safeguarding vulnerable adults, medication awareness, and health and safety. In addition, staff also receive specific training to meet individual needs. For example staff have had training in order to better support one of the men who lives there who has Parkinson's.

The staff at Pinecroft have made a positive change to the lives of the people who live there and are keen to share the good practice they have developed.

Case Study

Richard¹⁰ first moved to Pineroft in 2007 and has Asperger syndrome. He has also been diagnosed with schizophrenia and is subject to the Mental Health Act.

Richard's index offence was arson and he came to NAS services from generic mental health units with a history of absconding, lighting fires, self harm and homicidal urges.

After moving to NAS services, Richard's wellbeing has improved and his challenging behaviour has stopped.

Richard struggles with change and therefore needs time to adapt to transition. Initially, he preferred his own company and didn't cope well with other people in the same room. He would also shout loudly, talk to himself regularly, and speak about his paranoid thoughts.

Over the last five years, Richard's behaviour and mental wellbeing has significantly improved. He started to talk to staff about things that worry him, and also became tolerant and forthcoming towards other people in the house.

Richard has learnt to become more self-sufficient and has excelled in learning more day-to-day living skills, such as using the bus and administering his own medication. Richard is now actively involved in the running of the home, suggesting events and improvements that are then implemented by staff.

One of Richard's suggestions was to hold a firework party at Pineroft and after planning and a comprehensive risk assessment had been successfully completed, a party was held on New Year's Eve.

For the first time ever, Richard is starting to talk about moving on to more independent living in the future.

To learn more about the services on offer at Pineroft, please email services@nas.org.uk

¹⁰ Name has been changed

Dimensions – How Individual Service Funds can shift power and control

Dimensions is a not-for-profit organisation supporting nearly 3,000 people with learning disabilities and people with autism and their families throughout England and Wales. It employs over 5,000 staff and the services provided range from registered care homes through to supporting independent living.

Dimensions is committed to personalisation and its core aim is to support people to have real choice and control over their lives. Enabling people with learning disabilities and autism to lead more independent lives means supporting them to become much more involved in making their own choices and decisions – such as choosing who supports them, when and how. A personalised approach demonstrates positive outcomes, especially when support is developed in partnership with local authorities, families and other people who play an important role in the lives of the people being supported.

But a service can only be ‘personal’ if people have control over the funding to pay for support of their own choosing. In essence this means creating Individual Service Funds. An Individual Service Fund (ISF) is a sum of money managed by a service provider on behalf of an individual. The money provides support services for that individual which meet the criteria set out in their support plan. Services can be purchased from other providers. ISFs are being developed by councils to ensure people with managed budgets have the greatest possible choice and control within commissioned services, but the process can be slow.

Dimensions are determined to move to Individual Service Funds and has begun to develop ways to implement them within residential services that operate under traditional block contracts. Starting with a traditional care home, it enabled the six people supported to be in control of their own budget, choose their own activities, support staff and staff rotas. This involved determining how to allocate the existing funding to individuals in a fair and equitable way to reflect their individual needs, and devising a framework that would identify an individual allocation for each person supported; core support and shared costs; and a budget that people could control (‘in my personal control’). The people who live in the service now have support plans that look very different, based on what is important to them, on their skills and gifts, and how they choose to spend their time and personal budget. One of the people living in the ‘typical’ care home is Anne-Marie¹¹. She moved into the six-bed residential home having previously lived in a nearby long-stay hospital. We established an Individual Service Fund, working with her to plan her perfect week and draw up a community map to establish her existing relationships and explore opportunities to expand her connections in the community. As a result, Anne-Marie chooses who supports her with each of her personal activities, and how she spends her time.

Through this person-centred planning approach, Anne-Marie started to volunteer at a church coffee morning and began walking a neighbour’s dog regularly – two things she had always wanted to do in the community. Becoming more included in the community allows people to be less dependent on paid support, giving them

¹¹ A name she chose

greater control over their own budget and activities. Anne-Marie has joined new groups including a literacy and numeracy group which includes money skills, which should help Anne-Marie with her understanding of money and weekly budget planning¹².

Dimensions has found that if there is greater control for the people being supported as well as more inclusion, the relationship they have with the provider organisation and the people that support them radically alters – thus shifting the balance of power and control into the hands of the person with the Individual Service Fund. A recent example of this in relation to Anne-Marie was that she and two others at the home decided they no longer wanted to attend regular sessions run by another provider on communication and social skills and would rather use the money they were saving on alternative activities. This resulted in a letter of complaint to Dimensions from the provider that they were losing out on a valuable service. We responded that we were satisfied that the decision to cease was made by the people themselves, and that having ‘in my personal control’ money enabled the people we support to genuinely make their own choices about their activities. One challenge with this new approach is to manage more flexible staff teams and change the skills mix in order to deliver more choice to the people we support. This means changing the organisational culture away from fitting the people we support around our own internal structures to adapt our structures and working patterns around individuals and allocating resources effectively.

Dimensions works with 80 local authorities, many of which are now reducing funding. We are keen to ensure this does not mean a return to outdated models of commissioning and service design. Dimensions are convinced that working with local authorities and individuals to personalise support reduces unnecessary additional support and can save money over the longer-term.

More information about this work can be found in Making it Personal for Everyone, details on Dimensions website at www.dimensions-uk.org/makingitpersonal

Advocacy & Support

Good information and advice, including advocacy, is important to help people with challenging behaviour and their families to understand the care that is available to them and to make informed choices. But it is clear that there is a very wide variety in the quality and accessibility of information, advice and advocacy including peer advocacy and support to self-advocate.

Summary

Your Say¹³

Your Say is owned and managed by one person. It is an independent advocacy service which includes self-advocacy. It provides 1-1 advocacy and supports a number of self-advocacy groups including three networks in Bath and North East Somerset (BANES). The members run the networks, choose what should happen and how it should be done.

¹³ For more information see www.yoursay-advocacy.co.uk or www.banes-networks.co.uk

Your Say

The groups

Your Say runs self-advocacy groups attached to provider organisations. The groups tend to look at specific topics such as employment, social lives or issues related to the organisation such as home closures or organisational issues.

Your Say also runs the Bath and North East Somerset (B&NES) self-advocacy networks. There are three of these based in Bath, Midsomer Norton and Keynsham. The networks are open to anyone who believes they have a learning disability their supporters, carers, family members, providers and professionals in B&NES (so about 600 people). So far, the networks have engaged with at least 300 people. The networks were set up about six years ago, and the aim was to give people with learning disabilities a voice in B&NES. 'When we set the networks up, we found that people were used to sitting back and waiting for others to do something. Now we have a friendly but quite militant group of people who know there are things they would like improved in their lives and want to be active in making the changes happen'. The networks know things need to change and want to work in partnership with others to make things happen. This is important, as otherwise it can become people with learning disabilities 'against the world'. That is not how they work.

The networks are still interested in the Valuing People priorities of employment, housing, health and personalisation, but it is important for the networks to know about what this looks like locally. It is important to the networks that the work they do will make a difference to the members. They are not so interested in banging the drum nationally – though do make sure they keep themselves up to date with national issues and get involved when the group feel it is right to do so.

Your Say have spent quite a lot of time supporting people to understand representation, so they know it is not just about themselves but the group. 'As an organisation, we (the Advocates) don't do things for the networks, but do it 'with' them'. Having a supportive commissioner in B&NES has been very important. It has enabled Your Say to have time to grow the group between the meetings. It can take 20-30 hours preparation between meetings. It also gives Your Say someone to feed back to. The commissioner takes issues raised to the Health and Wellbeing Board. There are also regular formal meetings with the lead councillor, the commissioner and the network reps. The Partnership Board has been put on hold, but will be set up again. It may be handed to the networks to organise, but this has yet to be decided.

One of the network groups is very passionate about where they live (as lots of changes are planned). As one of the consulted groups in the community the members are very proud to be included in the decision making. They go to the town hall and ask to see any new plans. 'As supporters, we don't always know any more than the network members. For example, we didn't know about town planning and so our start was thinking with the network members about what we need to consider'. The networks include a significant number of people who would

be defined as having challenging behaviour and complex needs, although it is difficult to meet everyone's needs in a group setting.

A group of people in the Keynsham network, who would be described as having challenging behaviour (the group included someone who had been detained under the Mental Health Act), designed a training course called 'I am challenging, are you?' The course is designed to provoke thought and challenge attitudes. The trainers tell their stories and participants are asked questions like 'have you ever been so angry you have wanted to throw something?'. 'The training is currently targeted at staff, but we are planning to roll it out into the community.' A core group deliver the training but the whole network is involved. It can be difficult for people to talk about their experiences, but as one person said 'if I talk about my history, I hope it means it won't become someone else's history'.

'The on-going challenge for the network is to think about how we really become part of the local community. We are out there, but are we part of it? We are looking at how we can use our skills and knowledge to increase work opportunities for people with learning disabilities in their own community'.

Health

Health has been a priority for the B&NES network from day one. There has been constant communication with the commissioner regarding health work. Your Say developed a questionnaire for people attending their annual health check, in order to understand what should be in a health check, and did this through discussion with a friendly GP, and in collaboration with the commissioners and community nurses. The responses to the questionnaire go to the network for discussion and collation. This means the network members are able to talk with confidence about the findings. Your Say are just finishing a DVD on what people can expect from a health check.

The health check work was a collaborative process. The group knew that health was important, but weren't always clear if they had had a health check or what this meant. Your Say fed this back to the commissioner and community nurses who have recently been linked to GP practices, and know when people are being asked for a health check so they can support them if necessary.

Your Say have done work with the network members on what it means to be healthy. There is a lot of confusion about this. People were asked to do a daily exercise diary. One person recorded knitting as an exercise. Your Say have done work with the Bath Inclusive Sports and Activities group, and also do work on a healthy diet (5 a day and eat a rainbow). Some network members have weight related health concerns including obesity. There is a huge issue with informed choice about food. People who live in supported living can have shocking diets. Diet and health is often overlooked. Your Say have set up some social networks which are very popular. 'They are based on the 'Come dine with me' TV series. We cook a three course meal from scratch – these are always really well supported'. Your Say have done work on what it means to have specific ailments. What does it mean if you have a cold for example. They supported the PCT with accessible information about Swine Flu when that was a big concern a few years ago.

They have done 1-1 work with people who need medical treatment, and also support people to access their GP. This has improved in B&NES a lot since the community nurse link has been put in place.

People with learning disabilities are more likely to ask questions about health matters now in B&NES, and are more aware of their own health. 'But there are still real issues about the inequality of some health services for some of the individuals with whom we work.'

Family carers

Some family carers come to the networks. A cohort come regularly and support the groups in a variety of ways. The networks meet when people with learning disabilities want to meet (in the evening), which can be difficult for family carers. A group also come to conferences, and get meeting notes. They are very supportive. Your Say did interviews with them about what it means to be a family carer. They have quite a good link with the family carer network in Midsomer Norton.

1-1 advocacy

Your Say's 1-1 advocacy often informs their group advocacy. It is about empowering individuals. 'We give individuals the help they need to do it for themselves. We are commissioned on Block contract basis in a number of areas and will also do spot purchased advocacy. As the networks have grown, self-referrals for 1-1 advocacy have reduced in B&NES - because people feel more confident to check things out with us when they see us at Network activities. The 1-1 advocacy can be on difficult issues such as home closure, parenting issues, detention etc. We do get some revolving door clients, those individuals who come back to us to help with recurring issues or new issues as they arise'.

Parents with learning disabilities – the Parents 1st group

Through the 1-1 work Your Say found that parents with learning disabilities felt very isolated. They thought no one else was experiencing the same things they were. Bringing people together was helpful as they realised they were not on their own. It is a self-directed group. Your Say's role is to network people together. They don't sit down formally as a group, but Your Say can use them to consult on issues. They had some funding from Esmée Fairbairn which has enabled them to do some activities with the parents, and it has also enabled them to purchase bits and pieces to help the parents. For example, Your Say bought a school uniform once, when a child had to change schools.

Your Say get parents who come back on a regular basis. 'We haven't found enough changes to services in the last 10 years and parents with learning disabilities still very often are judged more harshly than others, but legal services (not courts) have improved. We have spent a lot of time nurturing solicitors. Some are very good. Just having a good solicitor can make all the difference.' 'I imagine Children's services love or hate us. They can be very good if we get involved early enough and can understand how we can support communication and help to build better working relationships. Once proceedings have started or a protection plan is in place it often becomes a 'them and us' situation which can make the situation more difficult for all parties. Unfortunately, as a lot of the people

we work with have borderline learning disabilities, there can be a delay while an eligibility assessment is done before we can start to engage’.

People with profound intellectual and multiple disabilities

A significant amount of Your Say’s 1-1 work is with people with profound intellectual and multiple disabilities. It is often about changes that are going to be imposed on the individual, so they are working on a best interests model. Although they collect a lot of information from people who know the individual, they can’t always rely just on that and spend an extended period of time, sometimes days, observing the individual in their environment, so that they can see what is really happening in their lives. ‘People get used to us and forget we are there. We bring a fresh pair of eyes to the situation. All situations are different. It is important not to think you know the answer’.

Bringing People Home

Sending people out of area into hospital or large residential settings can cause real harm to individuals by weakening their relationships with family and friends and taking them away from familiar places and community. It can damage continuity of care. It can also mean putting people into settings which they find stressful or frightening. This can damage mental health or increase the likelihood of challenging behaviour arising. The reasons for sending any individual out of area should always be clear and compelling. The individual and their family should always be involved and told about these reasons.

Summary

Beyond Limits

Beyond Limits have been commissioned by NHS Plymouth (now NEW Devon CCG) to develop local personalised commissioning/provider processes and tailor-made services for people who have experienced long term, multiple placements and institutionalised living because their behaviours have challenged existing services. They are piloting this through facilitating planning for 20 people currently in out of area Specialist Assessment & Treatment Units and then providing support using Individual Health Budgets.

Association for Supported Living (ASL)

ASL members contributed to a study on good commissioning in which they describe the ingredients to the successful outcomes they have achieved in moving people who at some point have been contained in institutions. Now everyone has a better life in community services which cost less. Prior to changes, costs ranged from £91,000 to £520,000 (for a private secure unit) per annum; following a move to supported living, high end costs reduced from £520,000 to £104,000 per annum.

Shared Lives Plus and Keyring

People labelled as 'challenging' have moved from care homes or 'assessment and referral units' into Shared Lives households, such that annual savings of up to £50,000 per person have been realised. The average saving is £13,000 per person. In one case, a move to a Shared Lives household saved the council £49,000 over twelve months, with further savings as the person was able to move into his own place with lower levels of support.

Beyond Limits:

Beyond Limits is an Organisation that has been developed to implement a 3-year project commissioned by NHS Plymouth (now NEW Devon CCG) as part of its response to the QIPP (Quality, Innovation, Productivity and Prevention) agenda. It is modelled on Partners for Inclusion in Scotland who have been providing tailor-made support to people with big reputations for over 12 years. Through a series of papers published by The Centre for Welfare Reform, and an evaluation by its Director, Simon Duffy, over this period, the Directors of Beyond Limits Sam Sly and Doreen Kelly (both Fellows of the Centre) and the NHS Plymouth Commissioner Gavin Thistlethwaite, will share learning, evaluate more personalised commissioning/provider processes and the impact of tailor-made services on the lives of people who have experienced long term, multiple placements and institutionalised living because their behaviours have challenged existing services.

The project is facilitating person-centred planning and implementing delivery of support to 20 people with learning disabilities and mental health needs who all originated in Plymouth but are currently in Specialist Hospitals and Assessment & Treatment Units miles away from their homes and families.

The aims of the project are to:

- Change health commissioning in Plymouth to be person-centred
- Develop indicative health budgets
- Change the culture of provision for people who are perceived to challenge services
- Provide person-centred support through detailed planning
- To completely stop the commissioning culture of placing people out of area and in specialist services

Project Planning and Design

The project is designed to develop the use of Individual Health Budgets (IHB) for people with learning disabilities and mental health needs with the outcome of truly individualised tailor-made services and the development of flexible ways to promote long term stability for people and the prevention of re-admission to Institutions of any nature including Specialist Hospitals.

As Plymouth is not a pilot site for IHB's, instead Individual Service Funds (ISF) are paid directly to Beyond Limits who with the involvement of the individual and their family will provide a flexible and responsive service to them.

Who we are working with

We are now into year two of the project and have facilitated service designs for 11 people and 6 working policies and 4 people have returned home. The people we are working with all have multiple labels including self-harm, or behaviours that harm others and property. People have:

- All have been abused
- Have moved between 6-25 institutions each

- The majority have been through the criminal justice system
- Youngest 27, oldest 58 years old
- First admission to an Institution aged between 14-22
- All been on MHA Section for between 5-14 years
- Been away from home for between a year and 16 years
- Many have moved to more and more secure accommodation as they have fought the system
- All families have felt loss of control, marginalised and physically unable to stay in touch
- All people have the same hopes and dreams as all of us

How we work

Every person's service is designed, from scratch, with only the person in mind, and modified in the light of experience and as things change. 'Service Design' is rooted in Beyond Limits commitment to help people achieve citizenship for themselves with the support they need and it is our fundamental belief that planning should be rooted in the positives; a person's strengths, gifts, talents and skills.

The Service design is facilitated for the individual and the people that know and care most about them (friends, family and present supporters). We plan together and out of this time comes information about where they want to live, what it will look like, who (if anyone) they want to share their life with, what they want to do with their life (hopes and dreams and everyday things), what support they might need and who they want to support them.

From this information adverts for a team are prepared with the person and their family and they are involved in the interviews. We recruit for the person based on their hobbies, interests, personalities (types of people who have worked well with them before) and on matching people up. Teams only work with one person so the match has to work for everyone. Matching seems to foster a depth of relationship and commitment rarely found in services where staff work with lots of different people.

Many great plans are made and then fall down because they are not followed up by a detailed 'how to' bit. It is fundamentally important that once a service is designed a 'how to' plan is written. Partners for Inclusion and Beyond Limits call this a Working Policy. The Working Policy is very detailed guidance (including what to do when things aren't going well) for staff and those others providing support. It is a living document updated with the knowledge gained as the team get to know the person well. Staff contracts are linked to the Working Policy and it is a disciplinary offence not to follow the guidance that the team has agreed is the right way to support the person.

Funding

NHS Plymouth is taking a truly innovative step as a commissioner and investing for long term gain rather than the usual short term vision that so often fails. The greatest reductions on ISF's will be seen after years two and three once the person's service is bedded in.

However, each on-going ISF is always less expensive than the previous hospital placement. Planning and pre-move transition is funded by NHS Plymouth (a one-off payment clawed back through reductions from years 2 onward) and the budget is slightly higher in the first year than the on-going budget to provide a flexible fund for the settling in period.

Decisions about the budget are controlled by those nearest to the person including their family and their team.

One person's story

Emma is a 28 year old woman from Plymouth who has been involved with services since a young child. She had a chaotic, traumatic childhood and went into care at the age of 14. Since that time she has lived in 25 different care settings including care homes, specialist schools, and assessment and treatment units as far away as Wales, Norfolk, and Bristol taking her 350 miles away from her family. She began to experience physical intervention as a form of managing the ways she communicated her anger at age 17 and was restrained on a regular basis until aged 26.

Emma was vulnerable and abused in her community and went through the criminal justice system when the way she communicated her distress led her to be violent and hurt herself and others. Emma was on a Section of the Mental Health Act for six years. Emma and her family were described by others as a problem. We started to plan with Emma when she was living in Bristol, but when the Winterbourne scandal happened Emma found cameramen camping outside the hospital she was in which made her frightened so she left on her own accord to return to Plymouth. The one thing Emma wanted more than anything was to be part of her family again.

Emma has been supported by Beyond Limits now for 11 months. She has a home of her own, furnished by her which she is proud of. She has a busy life which revolves around her family. There have been some real highs and equally some lows for Emma which is what happens in life. Emma has grown in confidence and now interviews for her team. Her support is flexible and adaptive so that if she is having a hard time staff can increase support, or take her away to diffuse things. She has a team that are committed to her. She has major health needs that are now stable and she is in control of them. She goes away regularly, and on the spur of the moment, to visit friends back in Bristol and Wales. She is well known in the hotel she stays in there. She has been to see Little Mix, JLS and Peter Andre and started ice skating lessons. Emma has just completed her CV and her next step is to get a job.

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Association for Supported Living:

STUDY INTO GOOD COMMISSIONING

Following the publication of the Association for Supported Living (ASL) report *“There is an Alternative”*, ASL members submitting the best practice stories¹⁴ for the report were asked to reflect on the commissioning process to describe the ingredients to the successful outcomes achieved.

Circumstances

Although every person’s story was different the common thread that ran through their lives was that at one time they were contained in institutions¹⁵ because their behaviours were deemed to be challenging. Now everyone has a better life in community services which cost less. Everyone was known to Health and Adult Social Care Services and many had been sectioned under the Mental Health Act at some time. Costs ranged from £91,000 to £520,000 (for a private secure unit) per annum.

What led Commissioners to make their decisions?

In some cases, regular planned placement reviews alerted the social worker to the person’s situation. In other cases it was the high cost of the placement or the fact that the person was placed a long way from home (out of borough/county) that would trigger a review, and in other cases planned service closures led to a search for alternative services.

This exercise revealed that it was good social work reviews which were personcentred and involved the person and their family, which led to finding alternative placements. (Often the family or social worker was unhappy with the treatment and the individual was in poor health, therefore there were concerns about the service provider). Social workers who were experienced, value-driven, and understood the various models of community support were best placed to construct good solutions, e.g. a social worker recognised the likelihood of a young person becoming a ‘life-long patient’ if they remained in the institution, that the service infantilised them and discouraged meaningful association.

Commissioning the Service

Although commissioners generally take a ‘tender’ route to select a provider these examples demonstrated that commissioners were willing to consider alternatives, namely by:

- Seeking expressions of interest from expert and experienced providers in managing complex behaviours in community settings with whom commissioners had contracts with or pre existing agreements (e.g. framework agreements).

¹⁴ Although only 10 stories were published, 38 examples were provided and 17 of these have formed the basis of this report.

¹⁵ Institutions were assessment & treatment centres, large residential settings, private & health secure units and a specialist residential school.

- Approaching a provider they had confidence in.
- Approaching a provider who also had access to housing.
- Approaching willing providers (not all providers have the confidence to provide services to people who challenge).
- Involving the person and their family in the selection process.

Why did it work?

Commissioning with Dedicated Lead

Where there was more than one person concerned with funding from different sources, having a single point of contact (project lead) gave consistency and continuity. Effective leadership which comprised good project management, with good communication skills and a willingness to take decisions contributed to the success of the commissioning process.

Commissioning was Outcome-Focused

Setting and monitoring person-centred outcomes, milestones and target dates for a range of independent skills successfully directed the focus of the person's support towards achievement and encouraged success.

Commissioning Bespoke Services

Services developed specially with the person and their family (and/or advocate) resulted in:

- The best possible support for the person.
- Equal focus on quality and cost.
- Valuing positive behavioural support.
- Staff recruitment and training targeted around the person.
- Taking advantage of leisure and other local facilities in the community.
- Effective use of assisted technology.
- Provision of suitable housing.

Commissioning in Partnership with Statutory Services

Having a clear commitment to working in partnership during and after transition, even when values might be different was beneficial. This included specialist Health and Adult Social Care teams working with the providers' teams initially intensively, reducing the level of support over time until eventually discharging the person from their care. Thereafter, having access to professionals without the need for referrals and being able to get advice early on contributed to the success of the service.

Commissioning with a Positive Approach to Risk Encouragement

Encouragement of risk contributed to the development of more effective ways of providing supporting. Further this helped to manage and divert high risk behaviour.

Commissioning a Transition Period

Commitment to fund transitional plans which involved double running costs, regular project planning meetings and realistic timescales for transition enabled the successful development of the service.

Commissioning using Flexible Funding Regimes

Having flexible funding worked well where there was:

- Acceptance that costs may be high when the service initially commences but with a clear plan for costs to reduce over time and at times of crisis there may be a need to increase costs.
- The agreement to fund flexible support hours and that the providers would return any un-used hours.
- Shared support with statutory services.
- Consideration to direct payments thereby giving full control to the individuals in line with the personalisation agenda.

Commissioning Authorities:

- Durham County Council
- Lancashire County Council
- Leicester City Council
- Lincolnshire County Council
- London Borough of Newham
- Somerset County Council
- South Tyneside Metropolitan Borough Council
- Vale of Glamorgan Council

Reduction in Cost Examples:

- Private secure unit £520,000 to supported living £104,000 (saving £416,000 per annum)
- Low secure residential unit £320,000 to supported living £91,000 (saving £229,000 per annum)
- Residential service £91,000 to independent accommodation £15,000 (saving £76,000 per annum)
- Private residential service £150,000 to supported living £70,000 (saving £80,000 per annum)
- Residential service £62,000 to shared lives £13,000 (saving £49,000 per annum)

The Association of Supported Living, May 2012

Shared Lives Plus and KeyRing

The Shared Lives sector and KeyRing Living Support Networks are two models which have been used successfully to enable people labelled as 'challenging' or who have 'complex needs' to move out of institutional settings into ordinary family homes and communities. These moves enable people to develop independent living skills, make new friends and move on with their lives, saving thousands of pounds in the process. This briefing outlines how these successful approaches, along with other community-based approaches, should be used as part of person-centred support planning to avoid the use of assessment and referral units.

In **Shared Lives** (www.SharedLivesPlus.org.uk), an adult (16+) who needs support and/or accommodation becomes a regular visitor to, or moves in with, a registered Shared Lives carer. Together, they share family and community life. In many cases the individual becomes a settled part of a supportive family, although Shared Lives is also used as day support, as breaks for unpaid family carers, as home from hospital care and as a stepping stone for someone to get their own place. Uniquely, Shared Lives carers and those they care for are matched for compatibility and then develop real relationships, with the carer acting as 'extended family', so that someone can live at the heart of their community in a supportive family setting.

Shared Lives is used by people with learning disabilities, people with mental health problems, older people, care leavers, disabled children becoming young adults, parents with learning disabilities and their children, people who misuse substances and (ex-)offenders. There are already 8,000 Shared Lives carers in the UK, recruited, trained and approved by 152 local schemes, which are regulated by the government's social care inspectors. In 2010, England's care inspectors gave 38% of Shared Lives schemes the top rating of excellent (three star): double the percentages for other forms of regulated care. When people labelled 'challenging' have moved from care homes or 'assessment and referral units' into Shared Lives households, annual savings of up to £50,000 per person have been realised. The average saving is £13,000 per person. Care inspectors, CQC, logged 3,473 safeguarding alerts and 39,115 safeguarding concerns related to social care provision in England 2011/12. Of those, 109 concerns and just one alert arose from Shared Lives.

KeyRing (www.KeyRing.org) is a community based approach which supports people in 'Living Support Networks'. In a KeyRing Network, people with support needs (Members) live in properties (from all types of tenure) in close proximity to each other. Each Member has their own tenancy, so if they move on from KeyRing support they do not have to move out of their home. Some Members already have somewhere to live when they join, but KeyRing supports most new Members to find a property.

The Network size can vary but there are usually nine people who receive support from a locally based Community Living Volunteer, who is usually housed in the Network area. Support from the volunteer is flexible and they provide support with things like helping the Member maintain their tenancy, dealing with letters and bills, and budgeting. Because they live in the Network, they are best placed to facilitate mutual (Member to Member) support, and help people to build links with the local

community. They can be the first port of call for any Member with a problem, and this often stops things escalating into a crisis. Members also come to support each other, as they get to know people and share their skills. KeyRing supports over 900 people in around 105 Networks across 43 Local Authority areas.

Case Studies

'Alan', 23, who has Asperger Syndrome, had moved between several expensive 'out of area' services, after his family and then a local residential service had found his behaviour and excessive drinking too challenging to manage. When he met the South Tyneside Shared Lives scheme, Alan said, "I hate it here and want to get out". Alan was carefully matched with registered Shared Lives carers and lived with them successfully for 12 months, accessing community education and rebuilding relationships within his community, before regaining enough confidence to move to his own tenancy, with occasional support. Alan's move to a Shared Lives household saved the council £49,000 over twelve months, with further savings as he was able to move into his own place with lower levels of support.

'Anthony' was placed in an out of area residential placement. The local authority recognised that this situation was not good for Anthony and his family. At the start of 2012 Anthony was supported to move back to his home area, initially to a local residential home. KeyRing were introduced and working with the care manager, community-based support began to be planned with Anthony. In June 2012, Anthony moved into his own accommodation as part of KeyRing Network. Anthony receives some additional one-to-one support from another provider with skills like cooking and shopping. This change has saved the council £11,000 pa, with further savings possible as Anthony develops skills and becomes less reliant on paid support.

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Websites:

KeyRing: www.KeyRing.org

Shared Lives Plus: www.SharedLivesPlus.org.uk

Shared Lives Plus works with social enterprise, Community Catalysts:
www.CommunityCatalysts.co.uk

Redesigning Services

The redesign of services is key if commissioners are to invest in flexible, good quality local services and away from sending people far away from home. There are robust examples of good practice where the focus is on providing intensive community support as far as possible with only limited use of in-patient services. Developing the capacity and capability of local services is critical in this. As part of the Department of Health Review we collated three in-depth case studies which highlight examples of good practice where there is minimal use of inpatient services for assessment and treatment (A&T) and setting out in some detail about how good services can be provided locally. These examples are from:

- Tower Hamlets,
- Salford and
- Cambridgeshire.

The case studies cover essential points around the range of services provided for people with learning disabilities or autism and behaviour described as challenging and the ways in which these areas have moved away from using Assessment & Treatment units and developed local services.

Below is a brief outline of the key features of each case study:

Tower Hamlets

- Genuine person centred, culturally appropriate health and social care helping to prevent the development of mental health problems
- A reactive service with a pooled budget that actively uses social care alternatives to hospital admission in a crisis
- Very close and intensive working with adult mental health services to allow use of crisis services and brief, focussed inpatient admissions in the generic mental health service

Salford

- Joint commissioning and use of pooled budget
- Strong links between health and local authority
- Clear joint working across multi-professionals
- Process to support people to return to Salford
- Partnership working with commissioned services
- Training for providers

Cambridge

- Person centred approach
- Joint commissioning of longstanding
- District-based services for people with Learning Disabilities
- Close links with other, specialised, mental health services

TOWER HAMLETS CASE STUDY

Services provided

Tower Hamlets is an inner London Borough. It has an estimated population in 2012 of about 252,440. It is estimated that there are about 6,000 people with a learning disability in the borough, with about 1,000 known to the community learning disability service, and about 750 people in receipt of services for people with learning disability. The population is relatively young, and about a third of adults and over half of the population under 18 are of Bangladeshi ethnicity. The population and learning disability factsheets from the Joint Strategic Needs Assessment give further details and are available here:

(http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx).

How services are commissioned

There is a pooled budget arrangement under section 75 of the NHS Act. Joint commissioning arrangements are in place which are led by the local authority.

The commissioning service support services that promote independence. Most people are supported to live independently and Tower Hamlets spends the second lowest proportion of gross social care expenditure on residential and nursing care for adults with a learning disability. However, due to complex and high needs it is necessary to commission residential and nursing care. In doing so we choose providers who offer safe and respectful practice that involves service users and their carers.

A brokerage service is used to identify providers that can meet an individual's needs and undertake financial negotiations.

How people at most risk are identified in planning, JSNAs etc

Based on the index of multiple deprivation Tower Hamlets is the third most deprived area in the country. Prevalence of learning disabilities in Tower Hamlets is generally high and tends to be higher in the Bangladeshi, south Asian and migrant communities in general which is believed to be due to poorer antenatal and neo natal care and poor access to health care.

The Joint Strategic Needs Assessment process in Tower Hamlets is robust and inclusive including representation from the community, statutory sector and service user and carer representation. There has been wide consultation on the outcomes in the JSNA and supports generally the principles of the recent Marmot /Review Fair Society 2010, which looks at the principles of improving health and wellbeing by reducing inequality and poor access to health care. As a result the Community Learning Disability Service is working closely with GPs and primary care professionals to ensure that annual health checks happen for people with learning disabilities thereby improving their chances of identifying common health problems such as diabetes and heart conditions.

Interdisciplinary community teams

We operate four integrated interdisciplinary teams within the community learning disability service, based on predominant client need. The four teams are

- Mental Health and Challenging Needs
- Community Health and Wellbeing
- Complex Physical Health
- Transition

Each team contains a range of health professionals and social workers. Each service user is allocated to a particular team, but staff within the learning disability service can work flexibly across the teams if this is the best way to meet the person's needs. Professionals within our team work together in a coordinated way to organise personalised social care, provide specialist healthcare interventions, and support people to access mainstream services.

For people with mental health problems and with challenging behaviour, we will provide direct psychology, psychiatry, nursing, occupational therapy and speech and language therapy interventions as appropriate to people's needs, and in an integrated manner. There will always be a lead professional, often the social worker, who will organise a flexible and person centred care package.

Other local services

Local Mental Health Services

We make extensive use of local mental health services, and play a very active role in supporting people with learning disability to do so. This is backed up by an agreed protocol with adult mental health services, and having the psychiatrists in the Community Learning Disability Service employed by the local mental health trust to enable local and strategic links. The services we mostly use are:

- **Adult mental health inpatient services:** for anyone with a mild or sometimes moderate learning disability who present with an acute mental illness requiring inpatient admission, this would be the first port of call. We support such admissions by providing detailed written clinical information including clinical and risk assessments, by close face to face liaison with the inpatient staff, especially the doctors, psychologists and nurses, by ensuring that someone from the learning disability team attends every ward round/decision making meeting, and by ensuring that discharges are not delayed, particularly by ensuring that social care required for discharge is provided in a timely manner.
- **Home Treatment Team:** this provides emergency treatment at home for people in mental health crisis, and supports discharge from hospital. We have established excellent relations with this team, and rather than handing over cases to them (as Community Mental Health Teams do) we co-work with them, doing joint visits within working hours, to support them to provide an out of hours service to our clients.

- **Psychiatric Liaison Service** at the Royal London Hospital – this service is where psychiatric assessments are carried on outside of working hours. If we suspect our service users will present we send information, and have ensured that our information systems are also accessible to them. They inform us whenever our services users present, and we liaise to develop appropriate follow up. All the psychiatrists in the learning disability service contribute to the rota providing this service.

Crisis Support

The Home Treatment Team described above is a crisis intervention service. We try to support people in mental health crisis in the community: at home in addition to the Home Treatment team we might provide extra support workers, and increased monitoring and review from clinical staff, especially nursing and psychiatry. Psychology can sometimes work with the client and their family to resolve the emotional and behavioural difficulties associated with the mental health crisis.

We can also provide other community options, particularly respite care, using the local respite services, but also other providers. We also provide emergency social care placements, e.g. in supported housing.

Use of assessment & treatment beds

There is no local assessment treatment service in the borough, the nearest is in Redbridge at Goodmayes Hospital. In the last 3 years, two people have used this service, both for just over a week. We have not used other assessment and treatment services in the past 3 years.

We do have 4 people in secure (forensic) inpatient services. These are all in the local service provided by East London NHS Foundation Trust. We work closely with this service to ensure people are discharge promptly and appropriately.

Involvement of people and their family carers

People and their carers are centrally involved in clinical decision making. We have also consulted service users and carers about out of area inpatient admissions. This led to the development of a local secure (forensic) service for people with learning disability, and all people needing forensic services are now receiving these locally, which is in line with the majority of users and carers views.

We also offer family interventions such as meetings to discuss their family member, and also more formal systemic therapy.

Changes made to the model of care and the key things to do in moving away from A&T units?

Several crucial factors contribute to this:

- Flexible social care provision is essential, so truly personalised care plans that really address people's needs are crucial.

- Integrated community teams and pooled budgets also, so admission is not seen as saving social care money.
- The community team does lots of work to facilitate access to mainstream mental health, without which people with learning disability are likely to be rejected from such services, or receive significantly suboptimal treatment.
- Cultural understanding is essential (In Tower Hamlets, many of the patients are from families of Bangladeshi heritage. Many families are keen to keep people in the family home, provided they have culturally appropriate support, so we work hard to provide this.).
- Much of the work of the service is aimed at preventing mental health problems and challenging behaviour.
- Person centred planning that genuinely incorporates choice, promoting independence, regular exercise, constructive activity, and healthy lifestyles all help address this.
- We also offer counselling and therapy to people with learning disability and their carers and families that can help to address problems early on.

In terms of outcomes, we have very low use of assessment and treatment beds, and the admissions we have are very short. We do not have long admissions to adult mental health, as we work to get people out as quickly as possible. We are able to provide a reactive service, so relapse of mental health problems is picked up early and hopefully prevent costs that would be incurred if treatment were delayed and the relapse more severe.

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SALFORD CASE STUDY

Services provided

The city of Salford covers 37 square miles in eight districts of Salford; the population is approx 220,000. Salford is an Inner City urban environment with a developing economy based on organisations such as the BBC coming here. In terms of numbers of people with learning disabilities within Salford, there are about 350 children and 800 adults who are on the dedicated registers.

National data suggests that about 0.6% of the population have a severe/profound learning disability and about 2.5% have a mild/moderate learning disability

How services are commissioned

The model of support operated in Salford looks to change the environment in which people live and reduce their frustration and challenging behaviour. We have been long-term supporters of Mansell. We have two priorities: that people remain living in Salford and that any Salford resident is supported to return to Salford. This requires capacity building of local services and skilling up staff throughout the service with a strong clinical lead from Psychiatry and Psychology.

Since 2002 Salford has successfully managed a Pooled Budget between Salford City Council and Salford NHS via section 75 of the Health Act. This has helped the setting up of a seamless one point of entry service where support is not divided into Health and Social Care. At the same time a model of joint commissioning was introduced in line with Valuing People in 2001. Like Mansell, the values inherent in Valuing People are central to the support we offer. This requires a strong commitment to advocacy, person centred support and planning with people.

A jointly managed integrated team was developed to implement shared risk taking but also manage the pooled budget. The pooled budget has a single responsible commissioner for learning disability who is managed by the assistant director for all joint commissioning in Salford.

Over the years strong Partnership arrangements have been developed with Health and City Council Departments to see people access the mainstream.

To assist with keeping people in Salford, Adult Social Care has Neighbourhoods, Culture, Leisure and Health Improvement in the same Directorate. This focuses staff on building choice and opportunities for people.

To assist with bringing people home, Salford has developed a coming home plan, which guides staff through the process of returning people to Salford. In the development of this Salford has a series of essential / catalytic / collaborative meetings that support the service to implement the coming home plan.

The coming home plan looks to develop and implement the messages within the Mansell report, and assist with the development of a diverse set of providers of which the service looks to help support to develop capability and capacity to support the most complex people.

A single service approach with clearly identified objectives allows the service to be flexible in returning people back to Salford and maintaining placements.

Strong links have also been built with adult safeguarding to ensure that safeguarding policies are implemented and are used as a proactive way to highlight issues but also identify working solutions, encouraging all providers to be transparent in the support provided.

Any commissioned service is based on the principle of ordinary homes in ordinary streets; therefore we try to apply the standard of an ordinary life where people are included as citizens. There is no residential care in Salford specific to people with Learning Difficulties. The whole service has a clear understanding of who the priority people are and this is constantly reviewed via the input they require from all parts of the service

Clear lines of communication have been established between management and case managers including allied health professionals.

There are a number of mechanisms that support future planning and service development, this includes Out of Area, Challenging behaviour Strategy group, Partnership board, staying health task group, transition task group, and Provider forum where Commissioners and Providers act collaboratively. Specialised commissioning liaison meetings. Specific Learning disability CQUINS developed annually with the local NHS foundation trust and mental health trust

Interdisciplinary community teams

The whole Learning disability service is managed by a single assistant director from Salford city council.

Community Team

- 1 Principal manager
- 2 Team managers
- 1 Health facilitator
- 1 Senior Practitioner
- 8 Learning Disability Nurses
- 5 Social workers
- 1 Carers Social worker
- 5 Community Assessment officers
- 1 Transition worker

The community team are divided into the eight districts of Salford, people supported are then allocated to appropriate workers within the patch. This helps links with Community Services. All members of the community team are allocated referrals via a central contact centre, and people are supported according to need and priority. Each house where people live has a Coordinator from the team rather than each person having a different worker. The community team operate a duty system which also incorporates PACE duty and DOLS referrals. Each patch is allocated a number of out of area individuals to ensure all reviews are actioned and regular contact is maintained. Members of the community team also chair safeguarding meetings and manage with support the Salford safeguarding process.

If individuals require specialist assessment or interventions by LDHP then an internal referral system exists. LDHP team consists of

- 1 Consultant Psychologist 1 WTE (1 Clinical psychologist, 1 Clinical Nurse Specialist, 1 Psychology Assistant all 1WTE, 0.2 WTE volunteer Psychology Assistant,0.6WTE trainee Clinical Psychologist)
- 1 AHP manager 0.4WTE (SALT 1 WTE, Physio 2WTE, OT 1 WTE, 1.6WTE Art therapy 1 Total communicator co-ordinator 1 WTE)
- 1 consultant Clinical Psychiatrist (1 SPR 1 SHO)

The LDHP team hold weekly referral meetings to allocate individuals to the most appropriate professional pathway, this assists with identifying and allocating priority people and may include people who are out of area.

The clinical psychology team with the LD service take the clinical lead in the process of bringing people back to Salford and prevention of placement breakdown, and the community team take the commissioning lead.

Another main workstream for the psychology team is the development of capacity and capability of the wider workforce of commissioned services in Salford and families. The psychology team hold regular meetings with managers from community team to ensure appropriate allocation and priority to referrals

Services commissioned in Salford

- Day Services x 3 (Staff employed by SCC) within day service a Development Team which consists of (2 WTE Person centred planning workers, 1 WTE development workers for learning disability services,1 WTE Autism development worker
- Short-term Breaks (1 Respite centre) (Staff employed by SCC)
- Shared Lives Adult placement (Staff employed by SCC)
- Supported tenancy service -16 properties (Staff employed by SCC)
- Supported Tenancy service (independent providers +40 properties)
- Supported employment
- Garden centre (Social enterprise)
- Individualised community support as required for individuals

Other local services

As outlined above, there is a strong commitment to opening up ordinary opportunities and multi agency working. There are also partnerships within Health and Social Care with an emphasis on joint working with Mental Health.

- There is a Full time dedicated Learning Disability psychiatry team, which links in with Learning Disability management systems
- Joint working protocols with MH, LD service and older adults
- Joint care co-ordination between LD and MH for identified individuals
- Training of generic mental health services i.e. IAPT
- Use of community mental health teams for routine support for individuals in the community who have LD and MH
- Use of beds at local generic mental health trust
- Links with older adult service for dementia services,
- Links with other services across the northwest to ensure sharing of best practice

Crisis Support

As the service seeks to plan support, there are very few crises and people continue to live in the same place. In eight years there have been 5 breakdowns of placement with three people returning to Salford to live within two years of the crisis happening. There are no dedicated special teams or Residential care beds as we have built up capacity in the overall service to support people through their frustrations in their living situation.

In response to a crisis, there are clear policy and procedure guidelines which seek a measured and supportive reaction to challenges. The Challenging Behaviour Policy highlights the use of the Challenging behaviour service leads as first point of advice and support.

Early intervention support is also provided by the challenging behaviour pathway in terms of challenging behaviour consultation sessions, training. Detailed communication between psychiatry, psychology team and community teams. The success of this can be seen from the fact that only 6 people have a written up programme for physical intervention. This figure has diminished over the last 5 years.

Physical health checks or interventions, including admissions, are seen as a clear priority and this may involve the use of our links with the local hospital via their assistant director for safeguarding who will liaise with appropriate hospital departments to ensure a joined up approach or development of individualised hospital admission pathways.

Salford does not have a specific crisis team, but utilises mechanisms highlighted above to assist with early identification to situations and prompt input at this early stage.

The workforce of commissioned services has free access to training around challenging behaviour including crisis management. This training is clearly monitored and staff are required to regularly attend updates. The training concentrates on very clear proactive positive behaviour strategies as well as covering least restrictive reactive strategies. Where required additional hours are commissioned for people, this may be to facilitate environmental changes for the person in crisis which may include consideration of service changes required for the person to continue to live in their home.

As part of a multi-agency approach there has been research into staff burnout and expressed emotion when dealing with challenging behaviour and also research into friendships. There has been Involvement with Liverpool LD services and Liverpool University in Human rights risk assessments and least restrictive support strategies. Use of annual restrictive practice audit across all services commissioned in Salford.

Data is collected about individuals and services in relation to frequency, severity of incidents of challenging behaviour. There is ongoing development of Salford wide challenging behaviour policy which all providers sign up to. The policy is used to

ensure that the least restrictive practices are used rather than to improve the way staff restrain people. An easy read version of this policy has been developed by people supported in Salford.

Use of assessment & treatment beds

Over the last three years we have only had one requirement for an assessment and treatment unit and this initially used local mental health service before transfer to specific unit that had been individually identified as being able to provide short term rehab until they were able to return to Salford. In the last three years the only other admission to secure setting has been a transfer from a HMP to secure hospital and this was facilitated via Northwest Specialised Commissioning.

Involvement of people and their family carers

There is a strong commitment to working in partnership with people and their carers. Person Centred Support and the advent of personalisation requires greater choice and control for people. The Partnership Board and sub groups work to see that planning, managing change and monitoring of progress is done together.

All training that is offered to staff is also offered to parents and carers. This helps with joint working with families as they have had the same information that staff receive to add to their expert knowledge of their family member. Within the assessment process, of either returning or maintaining placements, family involvement with the assessment process is paramount. Parents have also been involved in training of new staff who are to support their relatives. Parents and people supported have also played an active role in recruitment of new staff to the psychology team.

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CAMBRIDGESHIRE CASE STUDY

Services provided

Cambridgeshire is a predominately rural county with a population of approximately 600,000. Peterborough, previously part of the county, is now a unitary authority and has its own commissioning and providing arrangements for people with learning disabilities (LD). Based on the recommendations from the Department of Health Report published in 1993 by a group chaired by the late Professor Mansell (Services for adults with challenging behaviour and/or mental health needs), specialist community multidisciplinary teams for adults with LD were first developed in the south of Cambridgeshire in the mid 1990's. Ida Darwin Hospital was closed as a place of social care and funding was released for team development. At that time services in Fenland and Peterborough were provided by a different Trust and Huntingdonshire already had a community team. The strategy, jointly agreed by health and the Local Authority (LA), in accordance with Government policy (NHS and Community Care Act 1991), was to support the development of a market for social care providers from which social and day care services could be commissioned by the Local Authority (LA). In parallel, community-based interdisciplinary specialist health teams for adults with LD were developed to provide additional health expertise to people with LD and those providing support. The community teams were therefore established to ensure that particular skills were available to meet specific health needs, such as in the case of people with challenging behaviour and/or mental health needs, ensuring that accepted models for understanding, preventing and managing challenging behaviour could be applied. It was argued that social care providers could not be expected by themselves to have the range of expertise necessary and, where assessments were required because of concerns over challenging behaviour, these assessments would be undertaken by health disciplines in the teams in partnership with people with LD, families and other support providers under the aegis of the NHS.

Recent history

Since 2001, following the Health Act, the Local Authority, in the form of the Cambridgeshire Learning Disability Partnership (LDP), has been the lead authority for adult LD services across the county. Approximately 2400 adults with LD are known to the LDP although this represents only a proportion of adults with LD who live in the county. It is not policy to specifically identify and list people with challenging behaviour as any person with LD could potentially develop such problems and those that are presenting with challenging behaviour at one point may not continue to do so once the reasons for such behaviour have been identified and informed interventions undertaken. However, as described below, it is a core responsibility of those working in the community teams to work closely with those organisations commissioned to provide social support so as to develop strategies that minimise the risk of such behaviour and provide informed and theoretical sound interventions when someone is presenting with such difficulties. It was proposed that the model developed in the south of the county following the closure of Ida Darwin Hospital in the 1990's would be expanded across the county. However, this has not happened and recent investigations undertaken of the county-wide specialist LD services by the NIHR CLAHRC for Peterborough and

Cambridge have highlighted very specific structural and organisational difficulties that have impeded the subsequent development of the service (see below).

Commissioning arrangements

Cambridgeshire has joint commissioning arrangements with a pooled budget. In principle; the organisation and planning of the service is undertaken through shared protocols between the LA and the PCT, based on the joint strategic needs assessments. Cambridgeshire has recently been selected as having pathfinder status for LD as part of the clinical commissioning arrangements. At the regional level a Health and Wellbeing Board for LD has been established, chaired by a representative from one of the LAs.

District-based services for people with LD

Services for adults with LD in Cambridgeshire are configured in the following way. Social support (including day/employment opportunities) is commissioned by the LDP and provided by a number of third sector and private social care organisations across the county. All people with LD are registered with a general practitioner, who is responsible for general health matters and for annual health checks. Everyone has access to generic secondary health care services with support to access, such care being provided by families or by whichever third sector or independent organisation is commissioned to provide social support. The level of that paid support, however, is very dependent on whether or not the given individual meets the necessary eligibility criteria and how individuals spend their personal budgets. There are five integrated (i.e. joint with health and the LA) interdisciplinary community teams for adults with LD across the county – City, East, Fenland, Huntingdon, and South. These teams serve local populations of between 80,000 to 180,000. Because of historic variations across the county in service developments there are differences in team resources but in principle each team has the following disciplines, either in the teams or available to them as and when necessary: art and music therapy, care management, clinical psychology; occupational therapy; physiotherapy; specialist LD psychiatry; specialist LD nursing; and speech and language therapy. Some teams have chosen to have behavioural nurse specialists. The teams are directly managed by the LDP with care managers employed by the LA and health professionals employed by Cambridge and Peterborough Foundation NHS Trust (CPFT). Each team has a team manager who is answerable to an area manager.

When services were developed in the south of the county the case was made for district-based community teams with the above disciplines on the basis of need, the general nature and extent of need being determined through published research and on the understanding that there were certain needs that could not readily be met through existing generic services. In summary these include the following: discharging the LA's responsibility for care management under the NHS and Community Care Act; more general tasks such as working with social care providers to establish appropriate communication strategies in people's homes (visual timetables, use of makaton, etc); guidance about specific health matters perhaps relating to someone with a specific syndrome, support for further skills development, guidance and support when accessing secondary care services, and matters relating to adult life such as relationships and sexuality. In addition it was

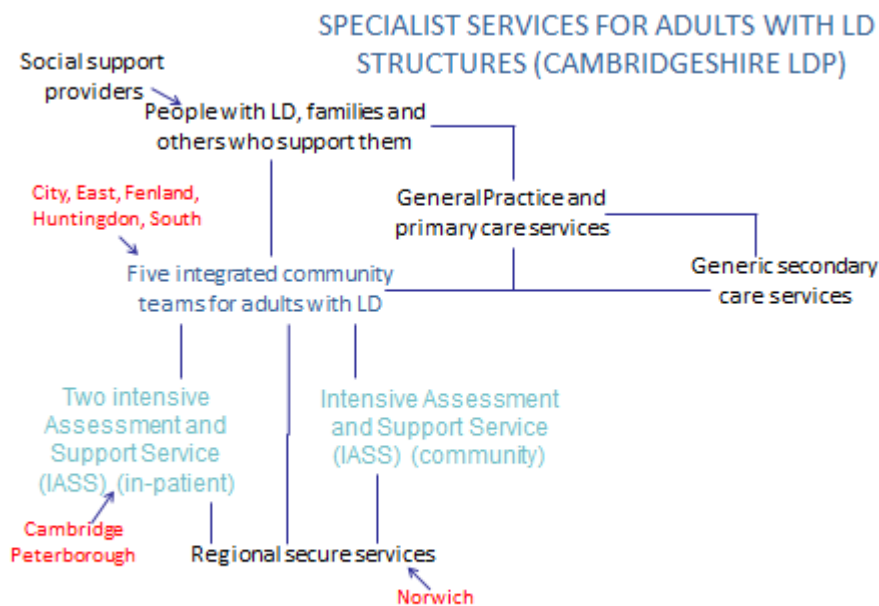
proposed that the teams should be directly responsible for assessment and treatment in four specific areas of health where multi-disciplinary involvement is often essential and where generic services are not readily able to provide such services: a) mental ill-health and challenging behaviour (the commonest cause of carer stress and placement breakdown); b) the need for assistance with eating and drinking in cases of dysphagia or for other reasons (to reduce the risk of associated morbidity and mortality); c) epilepsy (in collaboration with neurologists), particularly where such epilepsy is complex or associated with behaviour problems or mental state abnormalities (to reduce the risk of sudden epilepsy related deaths and to improve wellbeing); and d) interfacing with the criminal justice agencies if a person with LD was suspected, charged or convicted of an offence (to ensure access to justice and the necessary interventions in partnership with criminal justice agencies). In these four areas the teams would be seen as having lead responsibility, but in discharging these responsibilities may also link with other services if required.

Other specialist LD services

These interdisciplinary community teams are therefore the point of access on these matters and receive referrals directly from people with LD and/or their families or paid support workers, or from the GP. Together with primary care, it was also proposed that the community teams would support access to other generic services as and when it was appropriate, including access to mainstream mental health services if those services were the best to meet that person's needs at that point in time. It would clearly be discriminatory if that was not the case, but often needs relating to behaviour are not readily met by generic services and just as in other areas of health, more specialist support is required (as described below). In addition, community teams have direct access to two other local specialist LD services. First, there are two small in-patient NHS hospital-based services for people with LD who genuinely require temporary admission to hospital because of mental-ill health or for assessment because of being charged or convicted of an offence – one service is in Cambridge and one in Peterborough. In total 10 beds are commissioned by the LDP for the county. Although commissioned by the LDP these beds are directly managed by Cambridge and Peterborough Foundation NHS Trust. Secondly, originally funded for the south of the county only there is a tertiary team referred to as the Intensive Assessment and Support Service (IASS) community team. This is a small team with nursing, psychiatry, and psychology time that community teams can refer to when intensive work is required for someone in the community and teams do not have the resources that can readily be released to undertake such work. In practice the majority of people this team works with are those with severe challenging behaviour, some of whom have been convicted of serious offences – this team is similar to a crisis intervention team but in general receives its referrals through community teams (the only exception being when people are out-of-area then the IASS community team may be directly involved to bring them back into county). Absolutely essential to this model is the concept that the inpatient services and the IASS community team are resources for the district-based community teams to access. It is these community teams that have long term responsibility for working with individuals with LD and the organisation supporting them and if either of the other services becomes involved it is at the request of the teams and it is only on a temporary basis to undertake a specific task. A final resource is access to secure

hospital provision. This is not provided at a local level but in principle is available through NHS provision regionally (in Norwich and Hertfordshire) or through the private sector. Such provision should again be seen as a resource available to community teams and used only when secure hospital-based provision is genuinely needed and where assessment in such a setting, invariably under the MHA, is justified. This relationship has been problematic but it is crucial that admission to such services is via the local teams who have long term responsibility and that the purpose of the admission is clarified at the beginning and the local team remains involved.

Figure: Schematic representation of specialist LD services in Cambridgeshire



Crisis Support

Where a community team is working well it will have a strong presence in the geographic area it serves. There should be close links with people with LD and their families and also with social care providers, GPs and other agencies. It is these relationships and the quality of social support and the willingness of social care providers to work in partnership that reduces the risk of crises. Ideally all social care provision for people with LD should have appropriate communication strategies designed to help reduce anxiety and to aid understanding around complex concepts such as planning, time etc – particularly important for people with LD and additional autism spectrum disorders. Care plans should be developed based on a sound understanding of the person and his/her needs – people with LD are a highly heterogeneous group often with very specific and sometimes multiple health needs. Whilst social support is provided in the context of a social model, it is the application of other relevant models to an understanding of a person’s needs with respect to their health, behaviour and general functioning that can be critical in ensuring the success of care and preventing crises and placement breakdown. It is

the community teams that have this responsibility to respond to crises and they in turn have access to the other services mentioned above. Whilst there used to be an after-hours on call psychiatrist in LD, this is no longer the case. Primary care and mental health services are available after hours.

Assessment and treatment

LD services were conceived on the basis that assessment and treatment takes place wherever and in whatever setting it is required, most importantly in the community, in people's homes etc. It is not necessary, and may even be counter-productive, for assessment and treatment to be confined to 'an assessment and treatment unit'. The latter is only required under very specific situations, usually relating to the management of risk. The structure of services must support interdisciplinary and interagency working, and importantly, the opportunity for the relevant people to share understanding and arrive at a formulation that provides an appreciation of what may be predisposing to, precipitating and maintaining a particular behaviour, and to structure the formulation within a sound and informed theoretical framework. Such understanding may be based around the model of applied behavioural analysis (ABA), it may be informed by the identification of co-morbid physical or mental illness that may alter the propensity to such behaviour, it may be explained by particular risks known to be associated with specific causes of a person's LD, and there may be interactional and dynamic factors within the family or the social network of the person. Where intensive and urgent assessment and intervention is required the IASS community team is also available. Admission to the IASS in-patient service is primarily when a person is mentally unwell and may be a risk to him/herself or others and that risk cannot be readily managed where he/she lives. This tends to be people with mild LD who have limited social support. Where someone is charged and/or convicted of a serious offence and the courts are seeking guidance, admission under a hospital order to the local in-patient service may be indicated for assessment and perhaps later for treatment. Once convicted, if risk is small and can be managed further work may be undertaken in the community under a probation order or community treatment order. Where a person with an LD is convicted of a serious offence and the courts will expect a certain level of security then assessment and treatment in a secure setting may be indicated, with local services remaining involved and helping to direct the assessment process.

Involvement of people and their family carers

Since its inception the LDP has had a Board that has service user and carer representation and has been co-chaired by a service user. Care management and health staff in teams should ideally have close relationships with people with LD and their families, and this can be another important means of collaboration between different stakeholders. Given the fact that some people with LD will be unable to communicate easily and that challenging behaviour may be maintained (rather than reduced) by the responses of those supporting them, at an individual level when assessments are being undertaken and interventions developed, these partnerships are crucial. Families and support workers are a proxy source of information. Frequently the structured collection of data by them on a daily basis about the rates and nature of someone's behaviour, their mood etc, can be crucial in determining the underlying factors that might be predisposing to, precipitating

and maintaining aggression, self-injury etc. The task of the interdisciplinary team is very much to work in partnership to develop this understanding through the process of history taking, observation and formulation.

Models of care

The model outlined above was that developed in the mid 1990's with the strategic change that took place in Cambridgeshire in the south of the county with the closure of Ida Darwin Hospital as a place of social care. Its strength was that it, not only enabled the successful resettlement of people from the hospital, but with the establishment of community teams, many people were also brought back from inappropriate, often secure, hospital provision from out-of-area. In those parts of the county where services have been working effectively, people with LD and complex needs have been largely prevented from being sent out-of-area. However, people with LD as children have, until recently, still been going out-of-area and there are still parts of the county where adults are still too often sent to hospital or residential care out-of-area for reasons that are not entirely clear. A recent review of out-of-area placements in different settings suggests that the nature and extent of specialist community support and the function and attitudes of those working in services are key determinants for the prevention of out-of-area placements. The basic model of service was agreed at the time the LDP was established in 2001. However, since then there has been concern that specialist services have been eroded, and as temporary managers in the LDP have been in post, changes that do not have the full support of those in the service have taken place – as outlined below the key message is that informed and supportive management and a clear vision as to what a specialist service is there to do are absolutely crucial to maintaining such a service. Experience suggests that poor local services result in greater costs. The only case for out-of-area hospital placement is where secure provision is genuinely needed. In the case of social care provision teams need to work through care managers and commission local living arrangements that best meet the sometimes complex needs of an individual with LD. By developing local provision and avoiding placing those with such needs in out-of-area often large and isolated social care provision the LA is better able to ensure quality, monitor the person and the service he/she is receiving, and to manage and contain costs (as pointed out in the Mansell reports).

The specialist LD services in Cambridgeshire have recently been extensively studied as part of the NIHR CLAHRC for Cambridgeshire and Peterborough and these studies have identified significant problems that have arisen since the LDP was established. These are now being resolved with more sound and informed leadership but illustrate the potential complexity and fragility of such a network of services. The CLAHRC studies would indicate that key to an effective service is the recognition of the following: a) people with LD comprise a very heterogeneous group, some of whom have complex needs and that the services required must be inter-disciplinary, inter-agency, and community-based with the availability of specific additional resources; b) such specialist services are inevitably complex and because of this complexity it is essential to have an informed and respectful partnership and 'design leadership' between the LA (LDP), GP commissioning and the provider health Trust, who are together responsible for agreeing what the service is there to do and how it should be designed and function. In the absence of this there is the potential for chaos and for serious unintended consequences; c)

community teams in LD inevitably work at the interface with social care services and with a multitude of social care providers as well as with families and others. Understanding this interface is critical. Whilst social care providers should be expected to provide informed and trained staff they cannot be expected to provide all the knowledge and expertise to prevent and fully support all those with complex needs due to their behaviour and/or mental ill-health – it is for this reason that community expertise and partnerships are required; d) the nature and complexity of need for some individuals is such that the expertise of different disciplines and the bringing together of different models of understanding is required - specialist community services should be structured around a given geographic area and must be led in a manner that fosters inter-disciplinary working; e) there are cultural, legal, and conceptual differences between LA and health staff, which at its best bring strength to a services, although such differences must be understood and managed – for example, the LA is under local political control and its budget determined accordingly, the NHS is free at the point of contact, and there are issues around the sharing of health data and management styles and lines of accountability differ.

Conclusion

Outlined above is the model of service conceived for Cambridgeshire and which is provided to a variable degree across the county. This paper also outlines some of the problems in maintaining such a service and the importance of leadership and the understanding that an inevitably complex service such as this requires that it be designed and jointly managed, recognising and respecting the roles and responsibilities of different stakeholders.

Tony Holland

Cambridgeshire LDP and Cambridgeshire and Peterborough NHS Foundation Trust

May 2012

Quality Improvement

The primary responsibility for the quality of care rests with the providers of that care. Commissioners need to ensure that there is a good range of local services available to meet the specific needs of individuals that can be complex.

Dimensions:

Dimensions is a large social care provider that has made stringent efforts to monitor and improve quality and performance. It made a conscious decision to create a Compliance Audit Team separate from the operational management of services, believing that this tension would enable more objective and rigorous monitoring. The Dimensions Compliance Team, together with a team of four Experts by Experience, work across each of the organisation's regions conducting service audits. The audits look at every aspect of the service from regulatory requirements, finance, health and safety and for evidence of better practice, including a two hour observation of staff interacting with the people they are supporting as well as on-going observation throughout the visit. The audit process gives a clear picture of what is happening in individual services and across the organisation, and forms part of the reporting of risk management up through its governance structure, including the people it supports. The new systems are contributing to significant advances in quality and improved outcomes. Dimensions' intention is to promote best practice, ensure that it exceeds compliance requirements and demonstrate robust.

Dimensions - Focusing on quality improvement in adult social care

Dimensions is a not-for-profit organisation supporting nearly 3,000 people with learning disabilities and people with autism and their families throughout England and Wales. It employs over 5,000 staff and the services provided range from registered care homes through to supporting independent living.

The Quality Challenge

Like many large social care organisations, Dimensions shares the challenges of how to assure and improve quality across many sites and locations. In the last 18 months the organisation has re-structured to enable it to provide more personalised services and to better meet the requirements of the Care Quality Commission and other regulators. A significant focus has been in developing a number of initiatives, from service audits to risk management, reporting right through its governance structure. Together, these systems are contributing to significant advances and improved outcomes for the people we support.

The Internal Compliance Team

In response to the changing demands and requirements of the internal and external environment, we have developed the 'Dimensions Standards'. They are built around the regulatory requirements Dimensions is subject to, but go beyond compliance to raise expectations and make it clear that best practice approaches are a fundamental requirement of the organisation.

In order to monitor and improve performance against these standards, Dimensions has created a centralised audit function – the Dimensions Compliance Team. Its 17 members work across each of the organisation's regions. There is a programme of face-to-face audit visits by the team; all services receive an annual audit over one or two days and further quarterly half-day audits throughout the year. The audits look at every aspect of the service from regulatory requirements, finance, health and safety and for evidence of better practice. Every visit includes a two hour observation of staff interacting with the people they are supporting as well as on-going observation throughout the visit.

This way of working gives us a more rigorous and independent approach: now we aren't just asking if a member of staff is aware of a particular policy, but requiring awareness and evidence of the policy guidance in practice. At the end of the visit the auditor discusses headline feedback with the manager and will then write a full report. Where any issues are identified, the report is copied to the relevant function to enable them to support the service to address it, such as Behaviour Support or Performance Coaching.

Dimensions has made a conscious decision to create a Compliance Audit Team that was separate from operational management of services. This means that the audit process gives us a clear picture of what is happening in individual services and across the organisation.

Involvement of people and their family carers

Getting feedback from the people whom the service supports is an important part of every audit. Prior to the visit the auditor writes to people using an easy-to-understand format and including a photo and a one page profile of the auditor. (All our staff are asked to have one page profiles, one of the person-centred thinking tools in everyday use at Dimensions.) This means people know a little bit about the auditor and why they want to talk to them ahead of the visit.

In addition to the Compliance Team, Dimensions also employs four people with learning disabilities as Experts by Experience. They undertake Quality Audits following the Reach II standards, which focus on 11 standards that people with learning disabilities can expect in supported living environments.

Like most social care organisations, Dimensions has systems to collect customer satisfaction information from the people it supports as well as monitoring the views of families and relatives. Dimensions conducts annual 'customer satisfaction surveys' with all the people it supports. Every year it tries to improve both the accessibility and rigour of the survey to make it both meaningful and independent.

The next stage of development is to involve family carers more fully in the 360 feedback process. A new set of commitments to family members has been agreed and is being shared with family members. Families are already involved in person-centred reviews and in the support planning process now rolled out across the organisation.

Reporting measures

The Compliance Team reviews findings across the organisation and reports to the Executive Team and Board on key themes and emergent trends, as well as identifying issues to address and improve such as medication policies, financial scrutiny and any policy gaps. The new systems have shown significant improvements in terms of people working in a clear and consistent way, that services are improving their performance against the standards, and people feel much clearer about what quality means within their service and their role in achieving it.

Crucially, audit results feed into the business performance metrics framework. Strategic metrics provide critical information about how the organisation is performing. Our measures are in line with what's critical to the success of the organisation and our key business risks as detailed in our risk management plan. Having the right measures tell us important information about how well we are performing.

Having established a system where the compliance audits, performance measures and person-centred support planning all feed our business systems, we are now working on sharing the results more widely throughout the organisation and with people we support. We are working through the process to introduce reporting measures through the regional network of Everybody Counts groups, and up to the Dimensions Council. These groups are made up of people we support and form part of our governance structure. Our intention is to promote best practice, ensure

that we exceed compliance requirements and demonstrate robust and rigorous processes of internal scrutiny in line with our vision and values.

**We measure our success informally and formally. We constantly ask ourselves ‘what does good look like?’ for the projects we are working on, reviewing each of them and looking at any lessons learnt
We seek the views and listen to the people we support, their families and to our employees and partners to influence and shape organisational direction and success.**

Example - Influencing great engagement

Dimensions' Compliance Audit Team went into a supported living service in East Anglia, where three people lived. One person had complex needs and at times presented behaviours that challenged, one person was on the autistic spectrum and one person had moderate to severe learning disabilities. The audit observation process identified some areas where engagement between the staff and the people we support could be improved. The audit scoring and reporting process meant that the service was 'flagged' to trigger a response from the internal support functions within the Dimensions 'resource ring'.

One of the Dimensions Better Practice coaches went to the service for a day to undertake a formal observation and to review the support plans. Following the assessment, a development day was held with the staff team at the service, the managers, a Behaviour Support Analyst, a Performance Coach as well as a Better Practice Coach. This multi-faceted approach led to further training in promoting active support and positive engagement. The results saw the people that live there more meaningfully engaged in their lives and the following audit saw scores more than doubled for active support and engagement. The emphasis on objective scrutiny is not just about ensuring compliance but promoting the positive values and behaviours that Dimensions stands for.

More information about this work can be found in Making it Personal for Everyone, details on Dimensions website at www.dimensions-uk.org/makingitpersonal

Better Safeguarding

Delivering “SAFE” post Winterbourne: the role of local Safeguarding Adults Boards

On 22 October 2012, the Surrey SAB convened a major conference attended by over 250 users, carers and people working across all agencies engaged with adults at risk. A local action plan is also being developed there in response to the suggestions made by delegates.

In developing Southampton’s response to the Winterbourne scandal, the collective mantra has been to accept the proposition that “it could happen here, but we are determined it will not”. Accordingly, Southampton is using the Winterbourne findings and recommendations to undertake a fundamental rethink about how the SAB should be assuring itself about the quality of local safeguarding policy, procedures and practice, prompting and producing sustainable improvement. As Independent Chair, I have asked that our Winterbourne action plan is set within a clear strategic framework – so that existing action plans (e.g., those arising from Serious Case Reviews) are properly aligned, Business Plan priorities and targets are met and progress is actively monitored. The framework I have suggested to local agencies is called SAFE.

Introduction

Responding to the issues raised and lessons gleaned from the Winterbourne View Hospital Serious Case Review, the subsequent inspection programme by the Care Quality Commission and this summer’s interim report by the Department of Health demands that Safeguarding Adults Boards (SABs) act with alacrity, assertiveness and authority.

At the local level, the SAB already constitutes the leadership arena within which all agencies serving adults at risk develop and deliver adult safeguarding processes and outcomes. The forthcoming statutory footing for SABs, however, is welcome: it will help ensure that local safeguarding adults systems, practice and outcomes across all agencies receive the necessary priority, profile and performance management. Sector led initiatives such as peer reviews are proving to be of considerable help and support to SABs as they grapple with how they can best further their influence and impact in preventing, identifying and responding to the neglect and abuse experienced by adults at risk – but the lessons and recommendations from Winterbourne provide yet further fillip to SABs’ efforts to improve their effectiveness.

As the Independent Chair of Southampton’s SAB and the recent interim Independent Chair of Surrey’s SAB, I believe that a SAB must be:

- systematically informed by evidence – of outcomes, performance, best practice and learning and development
- obsessed with the quality of frontline professional practice and the experiences of frontline colleagues working directly with adults at risk

- characterised by mutual support and challenge
- accorded genuine organisational priority as revealed by effective governance and resource allocation (despite the financial austerity faced by all agencies) and, most importantly,
- engaged actively with adults at risk, their families and the community at large.

In Southampton, where we share our safeguarding policies and procedures with Hampshire, Portsmouth and the Isle of Wight, local agencies have developed a detailed action plan in response to the Winterbourne scandal. On 22 October, the Surrey SAB convened a major conference attended by over 250 users, carers and people working across all agencies engaged with adults at risk. A local action plan is also being developed there in response to the suggestions made by delegates. In developing Southampton's response to the Winterbourne scandal, the collective mantra has been to accept the proposition that "it could happen here, but we are determined it will not". Accordingly, Southampton is using the Winterbourne findings and recommendations to undertake a fundamental rethink about how the SAB should be assuring itself about the quality of local safeguarding policy, procedures and practice, prompting and producing sustainable improvement. As Independent Chair, I have asked that our Winterbourne action plan is set within a clear strategic framework – so that existing action plans (e.g., those arising from Serious Case Reviews) are properly aligned, Business Plan priorities and targets are met and progress is actively monitored. The framework I have suggested to local agencies is called SAFE.

The SSAB's role in relation to Winterbourne is the delivery of "SAFE"

Systems that work within and across organisations (in preventing, identifying and responding to safeguarding needs of adults at risk)

Accountability as commissioners and providers shared across organisations

Focused...on outcomes, performance, funding and learning

Engaged...with adults at risk, carers, providers, frontline professionals and wider public

Based on the recommendations set out in the Winterbourne View Serious Case Review, detailed actions plans accompany each of the four areas. Examples of the sorts of actions being implemented in Southampton are as follows:

Systems that work within and across organisations (in preventing, identifying and responding to needs of adults at risk)

- Audit of all Treatment and Assessment type services for people with learning disability and autism - find out what is known about existing standards of care
- Development of notification system (as with children looked after placed in a LA area) to adult safeguarding team by commissioning organisation
- Development of safeguarding trigger tool – so that individual episodes are used appropriately to prompt home/hospital/service level safeguarding investigations – this means CCGs, police and LA ensuring that all relevant info is captured (e.g., at A&E; GP out of hours; police call outs; notifications to HSE).
- Consideration of multi agency safeguarding hub – so that information, thresholds and responses given are accurate and consistent (potential for join up with children's safeguarding MASH)

Accountability (and governance) as commissioners and providers shared across organisations

- Section 11 type process introduced for all SAB agencies – this will address the quality of commissioning and service provision and ensure that each agency has detailed plans for improvement
- Responding to organisational change (e.g., CCGs, Health and Wellbeing Board, Police and Crime Commissioner) AND financial savings - need to support and challenge CCGs to have necessary commissioning capacity and capability and ensure that adult safeguarding is accorded priority (and therefore resources) by all statutory agencies
- Routine (bi annual?) reports by Independent Chair to Health and Wellbeing Board – detailing strengths and improvement priorities for partnership working in safeguarding adults
- CQC member to present annual feedback report to SSAB re local inspection findings and recommendations
- Review of SSAB Board structure – strengthening impact of user and carer experiences on how the Board operates and agrees its priorities, agendas etc and ensuring direct dialogue with full range of VCS and independent providers

Focused...on outcomes, performance, funding and learning

- Need to get reporting mechanisms right – review of PIs used in SAB’s performance scorecard so that mitigate risk of “episodic” approach – e.g., presentations at A&E collated by provider; calls to police from single address/service provider; Adult safeguarding team analyse by provider as well as individual; HSE referrals; use of control and restraint; absconding; complaints
- Annual reports by CCG and LA commissioners re their single/joint commissioning/decommissioning intentions, procurement activities and safeguarding adults assurance mechanisms
- SSAB to review multiagency guidance on standards re responding to whistleblowers – no passing the buck
- Development of “train the trainers” among local providers in delivery of safeguarding adults training and raising of standards
- Adult safeguarding team to keep updated register of “Registered Managers” – and introduce “achieving best practice” seminars with RMs
- Adult safeguarding team to keep register of all PAs – and ensure that alerts are analysed by PA

Engaged...with adults at risk, carers, providers, frontline professionals and wider public

- SAB to consider proposals for experts by experience (users and carers) to undertake (unannounced) reviews of adult safeguarding on behalf of SAB (NB: funding implication – and have to develop this WITH local providers). These reviews to be presented to SAB by the experts
- Issue SAB guidance to all providers detailing annual user and carer/family feedback re quality and safety of the care being received – this collated by SAB Business Office
- Annual meeting between SAB and all providers working with adults at risk across local area
- Introduction of the “Real life” agenda item at start of each SAB whereby frontline staff across different agencies present case studies explaining the response given to safeguarding concerns or alerts, highlighting what is working well and issues that the SAB needs to resolve

In Southampton, I am encouraged by the proactive response and progress made by local agencies for many of the “SAFE” action points set out above. For example, a notification system of people being placed by other areas in Southampton and a safeguarding trigger tool is now in place – with local agencies are working on the SAB performance report to ensure that the Board receives the relevant information. Equally, the Board has recently undertaken a review of its structures and refined its Business Plan for the forthcoming year. The Safeguarding team based in adult social care is keeping a register of Registered Managers – and

commissioners will be asked to use this to ensure that all services are appropriately managed. Like many other places, Southampton is currently addressing how best to establish its multi agency safeguarding hub. As Independent Chair, I will be checking to see how the adult Hub arrangements links with children's services – so that the SAB can be better assured that where parents posing safeguarding risks to children are also known to adult services, there is a more co-ordinated response.

The Winterbourne View Hospital scandal provides the Southampton SAB with a moral imperative to work in a very different way. The actions that we are taking in Southampton are designed to ensure that our SAB is much better engaged with those we serve, commissioners and providers. Our performance information will be more interagency and outcome focussed – as we recognise that the process and output measures that have dominated performance reports to date have been of limited value. And the financial austerity being experienced by all local agencies will encourage a more robust assessment of whether providers are delivering safe, personalised care that offers real value for money whilst – most importantly – safeguarding adults at risk consistently well.

Further Resources

Mencap and Bangor University

The Who's Challenging Who project

Who's Challenging Who (WCW) is an attitude change training package that has been developed over 18 months since January 2011 (pre-dating Winterbourne View). The development and pilot evaluation of WCW was funded by a *Knowledge Transfer Partnership* grant between Mencap and Bangor University.

WCW involves a person with learning disability who has behaviour that challenges working with a person without disability as co-trainers for a half day workshop targeting health and social care support staff.

The WCW training curriculum was informed jointly by the experiences of the co-trainers with learning disability and by existing research evidence. The theory behind the WCW training is to provide multiple opportunities for direct contact with individuals whose behaviour challenges and contact with information about their experiences of services and being labelled as "challenging". Small groups of support staff (up to 10) experience an intensive interactive session with the aim of increasing their empathy (what it is like to be in the shoes of individuals labelled as challenging), and changing their attitudes. An outline of Who's Challenging Who 2 Contact theory (the theory behind WCW) has already been used successfully to inform attitude change and reduce stigma towards other excluded groups, such as individuals with mental health difficulties.

For more information - <http://www.mencap.org.uk/wales/projects/who-s-challenging-who>

The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is a registered charity specialising in severe learning disabilities and behaviour described as challenging. Established by a family carer in 1997, the CBF works with families and professionals supporting children and adults across the UK. The CBF provides practical information and support to family carers and supports professionals and organisations with information, training and networking opportunities.

- **Family Support Service**

A non-judgemental telephone and email support service is available for family carers to access emotional support and relevant information from a Family Support Worker.

- **Resources**

The Challenging Behaviour Foundation has a range of 19 **information sheets** and 4 **DVD's** about challenging behaviour and related topics. All information sheets are free to download from www.challengingbehaviour.org.uk

Several longer guides are also available including "**A guide for Advocates**" a practical guide for advocates in supporting an individual with learning disabilities and behaviour described as challenging, to enable them to exercise their rights to the same life opportunities as everyone else. Aimed at professionals who commission services for individuals who display challenging behaviour "**Services for children who display challenging behaviour. Well matched and skilled staff**" by Dr Sarah Bernard and "**Services for adults who display challenging behaviour. Well matched and skilled staff**" by Dr Peter Baker gives an overview of what skills are required by the workforce and how to monitor services. See: <http://www.challengingbehaviour.org.uk/cbf-resources/commissioners-resources.html>

- **Positive Behaviour Support training**

Positive Behaviour Support workshops are available to help family carers and professionals develop individual positive behaviour support plans and to work in partnership. Evaluation has shown that following access to these workshops both family carers and professionals reported a reduction in the frequency and severity of challenging behaviour.

- **Challenging Behaviour – National Strategy Group**

The Challenging Behaviour – National Strategy Group (CB-NSG) is an action focussed group that works together to break down the barriers to enable children and adults with learning disabilities and behaviour described as challenging to have a good life. National meetings are held twice a year with action plans being implemented by members all year round.

Information, resources and links to best practice guides and key documents are on the website. For more information visit: www.challengingbehaviour.org.uk
Email: info@theCBF.org.uk Tel: **01634 838739**