

# KEEPING IN TOUCH WITH HOME:

HOW TO HELP CHILDREN AND YOUNG  
PEOPLE WITH LEARNING DISABILITIES AND  
THEIR FAMILIES KEEP IN TOUCH WHEN THEY  
ARE LIVING AWAY FROM HOME



## EXECUTIVE SUMMARY



The Challenging  
Behaviour Foundation



## WHY LOOK AT THIS ISSUE?

**THOUSANDS OF CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES LIVE AWAY FROM HOME FOR MUCH OF THEIR CHILDHOOD AND ADOLESCENCE, IN SPECIALIST RESIDENTIAL PLACEMENTS.**

Residential placements may be a positive choice, but for children with the most complex needs, they are often far from home, on a full-time basis and maintained for years. The challenges of keeping in touch with family and friends can be considerable, not least when children have severe learning disabilities and little or no verbal communication. Family bonds are so important to all children, but perhaps all the more to children who rely on those closest to them – typically parents and siblings – to understand what they want and to help communicate their wishes.

The research focused on children and young people aged 0-25 years with severe learning disabilities and behaviour described as challenging, including those with autistic spectrum disorders. Many of these children and young people have little or no verbal communication. Mental health problems are more prevalent in this cohort than their non-disabled peers. This combination of needs is common among children and young people in 52-week placements in residential special schools and children's homes. Some also spend months or even years as in-patients in mental health assessment and treatment units (ATUs), particularly during difficult transitions to adulthood.

The central message of this report is simple. **Children have a right to family life and to know and be cared for by their parents.<sup>1</sup>** The presumption should always be that families want to keep in touch and they should be supported to do so, if their child has to live away from home (including children sectioned under the Mental Health Act). This is so important to children and their loved ones - and with the right attitudes and the right support, it is possible.

## WHAT DOES THE REPORT COVER?

**THE MAIN AIM OF THE RESEARCH WAS TO PROMOTE GOOD PRACTICE IN HELPING CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES TO KEEP IN TOUCH, WHEN A RESIDENTIAL PLACEMENT HAS BEEN MADE. IT INCLUDES:**

1. **What works? Learning from families.** Families' vision of the support and attitudes needed to help them keep in touch and a summary of their experiences, both positive and negative.
2. **What works? Learning from local practice.** Case studies of practice in local settings which show much commitment to helping their young people to keep in touch with home and keeping families well informed and involved. 'Good practice' checklists.
3. **The legal framework.** An overview of legal rights and duties around keeping in touch with family and involvement in decision-making, covering human rights, education, social care and mental health legislation and guidance.

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1. Article 8 of the European Convention on Human Rights and Article 7 of the UN Convention on Rights of the Child

## RESEARCH FINDINGS

### WHAT DO FAMILIES OF CHILDREN AND YOUNG PEOPLE IN RESIDENTIAL PLACEMENTS WANT?

Learning directly from the experience of families with children (some now young adults) in residential placements was central to the research. This involved participating in a focus group, an online survey and a telephone interview. Twelve family-carers took part in this research. While this is a small sample and may not be representative, it provides valuable insights into the barriers

families can face in keeping in touch and involved, when a child has to live away from home. Their experiences also shine a light on many positive examples of individuals who were prepared to work flexibly to support family relationships. As one Mum told us: "Culture and attitudes make most difference. If these are right, then you can work out the logistics"



### KEY MESSAGES FROM THE FAMILIES INVOLVED IN THIS RESEARCH

#### Starting out in a new placement

1. Let me help you to get to know my child, what makes him happy or sad, how he communicates and what his behaviour means. Learn from me and be prepared to be flexible in your approach.
2. Let's sit down together at the outset and plan how we are going to keep in touch with our daughter while she is living away from home.
3. My son is not a blank page. He has a family, friends, a cultural identity, a history and a future. Help him to feel at home by reflecting who he is in his surroundings and activities.



## ACTIVE AND OPEN COMMUNICATION

4. I am a parent: I need to know if my child is happy, safe and well. I want to be kept informed day-to-day.
5. I want a trusting relationship with the key worker(s) caring for my child. I want us to communicate actively, enjoying the good moments and working together through challenging times. Involve me in problem-solving, I know my child better than anyone.

## SEEING MY CHILD REGULARLY

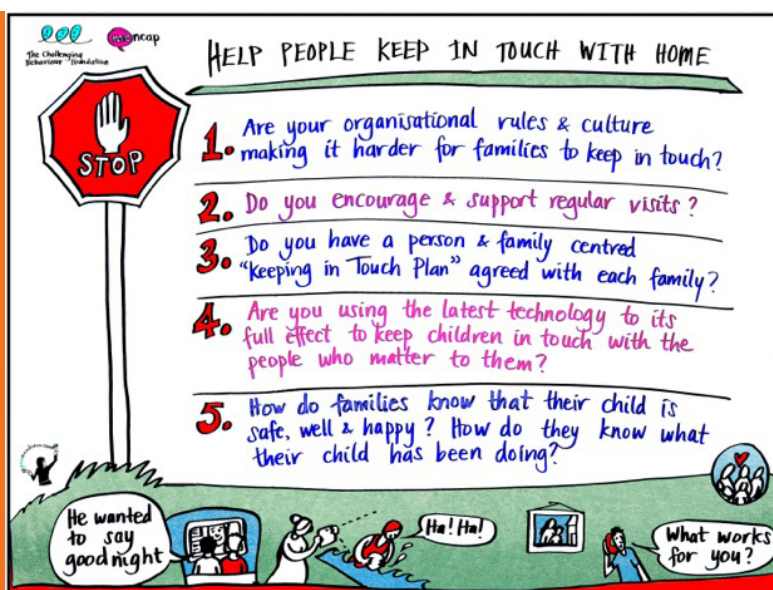
6. My son doesn't speak, so I need to see him to know all is well. Support him to use Skype (or similar) so we can see each other
7. Let me visit regularly and help us to make those visits a positive experience for all.

## RECOGNISING AND DEALING WITH EMOTIONS

8. I don't know if I will ever get over the pain of my daughter having to live away from home. Sometimes I feel overwhelmed and may need an advocate to help me to speak.
9. Sometimes we will disagree and sometimes things will go wrong. We need to work together when that happens. You need to see me as part of the solution, not part of the problem.

### STOP AND THINK!

### KEY QUESTIONS FOR SETTINGS AND COMMISSIONERS



## LEARNING FROM LOCAL PRACTICE

The report includes detailed case studies from three settings which show much commitment to keeping families informed, involved and in touch - two residential special schools and children's homes, providing 52-week placements and a residential specialist college.

Key elements of their practice are summarised in a checklist. We urge managers of residential settings for children and young people with learning disabilities to use this to review their policies and practice - including health in-patient settings such as assessment and treatment units, where the families involved in this research encountered some significant barriers to keeping in touch.

# GOOD PRACTICE CHECKLIST FOR RESIDENTIAL SETTINGS FOR CHILDREN AND YOUNG PEOPLE

## ATTITUDES AND VALUES

- 1 Value, support and promote families' on-going involvement in their child's life
- 2 Be sensitive to families' needs and the grief they may feel when their child moves away from home

## STARTING OUT

- 3 Arrange visits to familiarise the child/young person with the setting and provide a record for them to take away, in a suitable format
- Visit the family home to start to build relationships, share information and get to know the young person, their parents and siblings. Learn from the family about:
- 4
  - how their child communicates, involving them in developing pictures and symbols (e.g. PECs cards) to aid communication
  - their child's behaviour, involving them in developing a proactive approach
- 5 Expect some homesickness at first and involve family in planning how to ease the transition e.g. frequent visits at first, photos, music, familiar things from home

## PERSON-CENTRED PLANNING

- 6 With the young person and their family, explore who they want to keep in touch with and who or what they may miss most e.g. key people, interests, favourite food, music, pets. Can you provide some of this? Be sensitive to cultural identity.
- 7 Explore how families want to be kept informed, involved and in touch with their child and keep that under review; especially regarding incidents

## ON-GOING CONTACT AND UPDATES

- 8 Find the best way for each child to communicate regularly with family/friends at home
- 9 Involve the child in providing updates to home e.g. choosing which photos to share or using a template which they can fill in
- 10 Monitor contact from home, encourage and support more contact if necessary

## VISITS

- 11 Have an 'open door' policy for visits – allow families to visit whenever they want
- 12 Provide family-friendly visiting areas where families can enjoy private time together. If possible, provide accommodation for families visiting from afar

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**13** Invite families to join in activity days, information sessions and training. Provide opportunities for them to get to know each other and staff

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**14** For young people who have no-one to visit them, find a suitable befriender and advocate

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## COMMUNICATIONS TECHNOLOGY

**15** Exploit the potential of audio-visual technologies such as Skype and FaceTime to facilitate day-to-day contact with home, especially for non-verbal children

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**16** Use secure websites e.g. Wiki Online to facilitate information-sharing and an on-going dialogue between staff and families

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**17** Use social media e.g. a closed Facebook page to enable families to get to know each other and to provide an informal feedback channel

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**18** Have a staff member who is responsible for championing the use of new technologies to aid communication for children and young people

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## ADVOCACY

**19** Arrange regular visits from independent advocates, skilled in non-verbal communication, especially for children with little family contact

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## FAMILY FEEDBACK & STRATEGIC INFLUENCE

**20** Seek feedback from families (parents, carers, siblings, significant others) about how to improve communication between families and their children and with the setting. Give families a voice to influence the setting's practice and policies, through involvement in a forum with strategic influence.

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## CALL TO ACTION!

### PROMOTING GOOD PRACTICE


**We urge Local Authorities, health commissioners and residential settings to:**

- use the checklists in the report to review their policies and practice and to identify areas for improvement
- use the graphics in staff training and as a basis for discussion among senior managers, to explore how far attitudes and approaches measure up to families' expectations
- consult family-carers directly about how they would like to be kept informed, involved and in touch with their child or young person.

**We urge families** who have a child or young person living in a residential setting to use these resources to seek improvements, where needed.

### MEETING STATUTORY EXPECTATIONS

With the time and resource available for this project, it was not possible to evaluate how far local practice measures up to statutory expectations. But our research points to great variability in residential settings' attitudes and approaches upholding children and young people's right to family life; and a lack of engagement by placing authorities and service commissioners in promoting and supporting this. Further research is needed to explore this important issue further.



The gap between policy (generally positive) and practice (some positive, some serious concerns) was widest in respect of health in-patient assessment and treatment units (ATUs), where around 165 children and 725 young adults currently live.<sup>2</sup>

**We urge Transforming Care Partnerships now to:**

- ensure that they know how many children with learning disabilities, autism and behaviours that challenge are living in ATUs in their area
- explore policy and practice in ATUs and take action to promote family-friendly approaches
- share this resource with the families of all children and young people currently living in ATUs or in 52-week placements in residential special schools and children's homes, and encourage and support them to seek improvements in practice, where needed.

**We urge Local Authorities to:**

- use this resource to remind themselves of their legal duties towards disabled and vulnerable children living away from home (see Section Three: the Legal Framework in the main report).
- use the Local Offer to inform parents of disabled children in residential placements of the support to which they are entitled; and to ensure that such support is provided.

Lastly, we urge the **Department for Education, the Department of Health and NHS England** to act to address the lack of data, research and policy attention on disabled children living away from home.

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2. Initial data published by HSCIC on patients with a learning disability, autistic spectrum disorder and/or behaviour that challenges, who were inpatients at midnight on 30 September 2015; 18-25 year old data provided by special request.

## **The Challenging Behaviour Foundation (The CBF)**

The CBF was founded in 1997 by Vivien Cooper OBE, the parent of a child with severe learning disabilities and behaviour described as challenging. It is the only charity for people with severe learning disabilities who display behaviour described as challenging. The CBF makes a difference to the lives of children and adults across the UK by providing information and support to families and professionals; running workshops; and speaking up for families on a national level.

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### **General enquiries**

Email: [info@theCBF.org.uk](mailto:info@theCBF.org.uk)

Telephone: 01634 838739

### **information and support**

Email: [support@theCBF.org.uk](mailto:support@theCBF.org.uk)

Family Support Line: 0300 666 0126



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## **Mencap**

Mencap supports the 1.4 million people with a learning disability in the UK and their families and carers. Mencap fights to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want.

[www.mencap.org.uk](http://www.mencap.org.uk)



**The Challenging  
Behaviour Foundation**

