



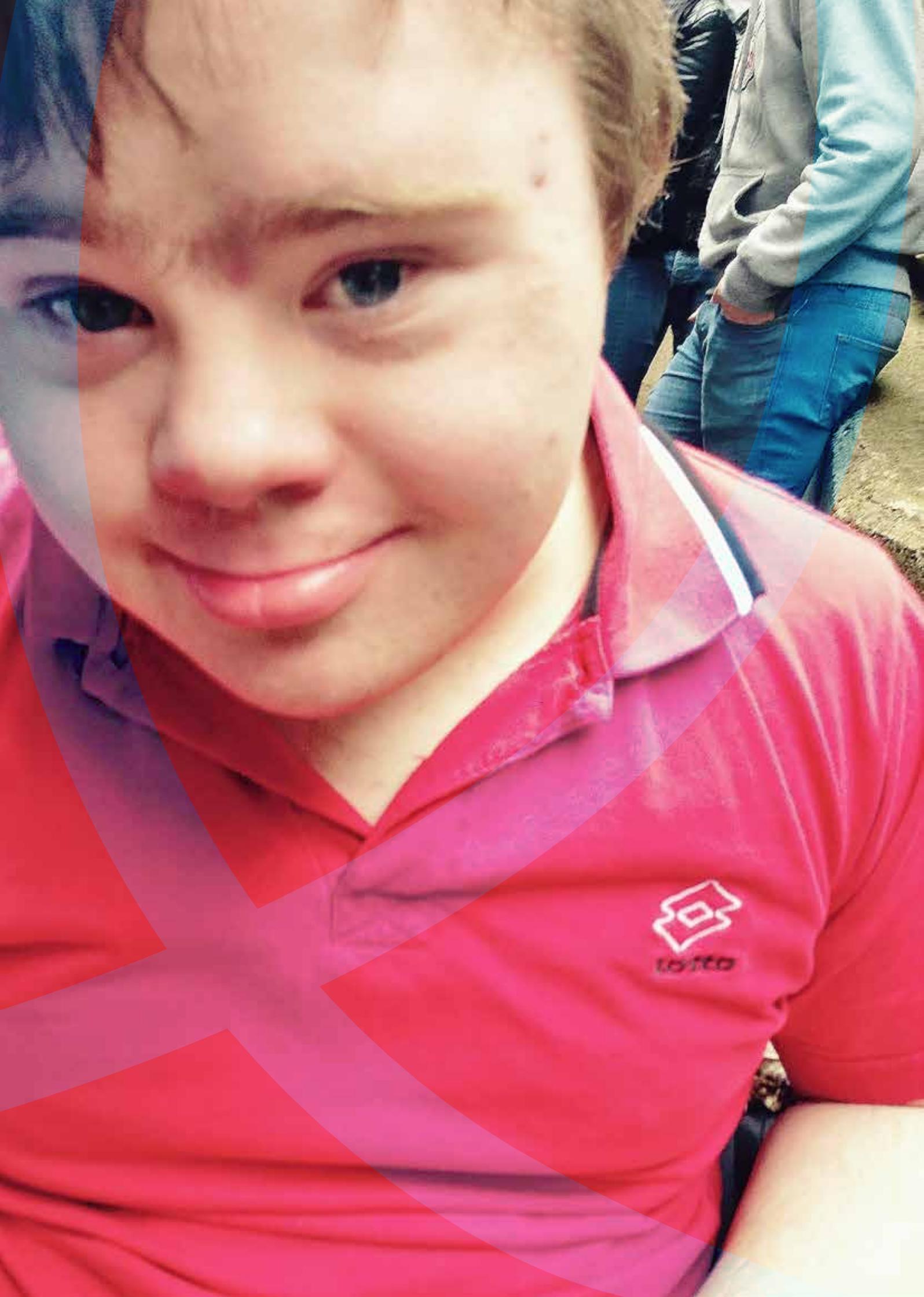
KEEPING IN TOUCH WITH HOME:

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



The Challenging Behaviour Foundation





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PRACTICAL RESOURCES TO DOWNLOAD

The main aim of this research was to promote good practice in helping children and families to keep in touch, when a residential placement has been made. This report includes resources to help local settings and service commissioners to review their policies and practice:

- 'What works?' checklist for settings
- 'What works?' checklist for Local Authorities and health commissioners
- Families' vision of good keeping in touch arrangements (colour graphic)
- Stop and Think! 5 key questions for residential settings and commissioners (colour graphic).

These can be downloaded from www.pavingtheway.works

INTRODUCTION

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. The data on them is poor, but we know that over 6000¹ children board in residential special schools, over 2000² young people attend specialist colleges on a residential basis, around 165³ under-18s and 725⁴ young adults (aged 18-25 years) are in-patients in mental health assessment and treatment units (ATUs) and an unknown number of disabled children (probably in the low thousands⁵) live in children's homes.

Residential placements can be a positive choice for young people and their families, for example, moving away from home to attend a specialist college may support the transition to independent living and adulthood. However some residential placements are made in a crisis situation, following a breakdown in local support and services and because specialist provision is not available locally.⁶

For children with the most complex needs, residential placements are often far from home, on a full-time basis and maintained for several years. The challenges of keeping in touch with family and friends at home 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 Challenging Behaviour Foundation (CBF), started by Vivien Cooper, whose son moved to a residential school over 275 miles away, supports families of people with learning disabilities and behaviours described as challenging. We know how devastating the 'shock of separation'⁷ can be when a child or young person moves away from home; and how difficult it is for even the most committed of parents to maintain a strong relationship with a child with limited communication skills, living on the other side of the country, while trying to balance the needs of other family members and the distance, time and financial cost. Unfortunately, unsupportive attitudes and inflexible rules in some settings add greatly to these challenges.

The central message running through this report is simple. **Children have a right to family life and to know and be cared for by their parents. The presumption should always be that families want to keep in touch and they should be supported to do so, if a child has to live away from home. This is so important to children and their loved ones - and with the right attitudes and the right support, it is possible.**

1. Office of the Children's Commissioner (2014) The views and experiences of children in residential special schools: overview report. London: OCC.
2. Data not collected, this is an estimate from the sector's representative body, Natspec.
3. 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. Available at <http://www.hscic.gov.uk/catalogue/PUB19428/ld-census-initial-sep15-rep.pdf>
4. Data request to HSCIC (this age breakdown was not published); details as in footnote above.
5. National statistics do not provide a clear figure due to problems with the way data is recorded. Residential special schools registered children's homes offer over 2,400 places (included in schools' total; Ofsted Children's Social Care statistics, March 2015). In addition, many disabled children who are looked after are placed in children's homes.
6. Gore et al, 2015, NIHR School for Social Care Research Scoping Review: Residential school placements for people aged under 25 with intellectual disabilities
7. Quote from a mother involved in this research.
8. Article 8 of the European Convention on Human Rights and Article 7 of the UN Convention on Rights of the Child.

WHICH CHILDREN AND YOUNG PEOPLE, IN WHICH SETTINGS?

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.

THIS REPORT

The main aim of this research was to promote good practice in helping children and families to keep in touch, when a residential placement has been made.

Section One draws on our research with families whose children or young people are in residential placements. It sets out their vision of the support and attitudes needed to help them keep in touch in a colour graphic. Key messages from families are summarised in nine themes, drawing out both positive and negative experiences.

Section Two provides three detailed 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. It concludes with checklists for local settings, local authorities and health commissioners, to help them to review their policies and practice.

Section Three provides a detailed overview of the legal framework, including human rights, education, social care and mental health legislation and guidance. Links are provided to expert legal briefings which are freely available online.

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 to 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 report concludes with a call to action to all those responsible for children and young people in residential placements - including Local Authorities, health commissioners, Transforming Care Partnerships and central Government - to drive much-needed improvements in policy and practice.

AUTHOR'S NOTE

This report represents the author's views, based on the research described above. My thanks to all who contributed, in particular the parents who shared their experiences with us and professionals in residential settings who got in touch to tell us about their practice. Thanks also to members of the advisory group for their insights and the wealth of experience they brought to this project; and to Vivien Cooper, Jacqui Shurlock and Brittany Mulhearn of the Challenging Behaviour Foundation and to James Robinson of Mencap for their support and valuable contributions to the research.

This research was developed as part of the 'Keeping in Touch with Home Project' delivered in partnership by the Challenging Behaviour Foundation and Mencap. The project hopes to improve the support offered to families to help them keep in touch with children who are living away from home for a long period, and is funded by NHS England as part of the Transforming Care Programme.

Anne Pinney, Independent Researcher,
June 2016

9. Schools offering 52-week placements are dual-registered as children's homes. Research ref.: Gore et al, 2015 (as before).

SUMMARY OF KEY MESSAGES FROM FAMILY-CARERS

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 may mean. 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.

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.

“ We prefer to get to know them ourselves. ”

“ Please don't visit in the first month. ”

Advice given to parents by new settings (an ATU and a residential special school respectively).

Several parents spoke of being asked to stay away when their child started in a new setting, to allow staff to get to know them 'on their own terms'. Even a residential special school which showed much commitment to supporting family visits and day-to-day contact, requested almost no information about their new starter from his parents.

One Mum reported that the Assessment and Treatment Unit (ATU) which her son had been admitted to in a crisis, assumed that she would drop him and leave; this was unthinkable at such a traumatic time, but the Unit's policy was that visits could cause anxiety and inhibit the patient's recovery. The Consultant relented and they established daily half hour visits and a strong working relationship, staying in a flat nearby throughout his treatment. The Consultant later observed that these parents had played a positive role in their son's recovery.

Another positive example involved a short break setting, which worked closely with a mother in preparing to look after her young person. She made videos to show for example, what her daughter enjoys

doing and how to help her in and out of the bath, to help train staff. This setting used 'intensive interaction'¹⁰ to improve communication and trained both their staff and the family in this technique, so that a consistent approach could be used at all times.

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.

One of the parents in our focus group made the simple suggestion that settings should agree a person-centred plan with families and young people about how they want to keep in touch, including visits, day-to-day contact and updates from staff. Surprisingly, none of the parents had ever had a plan of this sort. Those that achieved a good level of contact attributed this primarily to their own positive attitudes and determination. They also observed that none of their children had ever been asked, as far as they knew, who they would like to keep in touch with at home or how.

3. My child 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 this in his surroundings and activities.

“ It doesn't occur to them that he might want to know what's happening at home ”

Mother, son at residential special school

Part of keeping in touch with home involves keeping in touch with your own identity - the person you were before the residential placement and the life you expect to return to. One of the mothers in our focus group decorated her son's room and put up photos of his favourite places, people

10. An approach to teaching the pre-speech fundamentals of communication to children and adults who have severe learning difficulties and/or autism and who are still at an early stage of communication development.

and pets. He knew how to use Google Earth and liked to look at satellite images of home. When his family moved, the school supported him to get to know their new home, making short visits until he felt comfortable enough to spend the night there.

This contrasted with a young man from a minority ethnic background, whose settings seemingly do not appreciate the sensory significance of his cultural and religious background, including bright colours, cooking and prayers, which are not reflected in his daily life. Each visit by his mother starts with a hug and reciting a prayer together. This has a calming, reassuring effect and enables them to share a spiritual connection that has always been part of his life.

Ethnic identity is important. For example, a speech and language therapist made a symbol card to represent this young man, using a picture of someone from an obviously different ethnic group. Her son was confused when this card was offered to him to put with the picture for his family's home, inviting a visit home; presumably thinking that this meant some strange young man might stay there instead of him.

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.

Most parents received regular updates from their setting about what their child was doing day-to-day and whether they were well and happy. This tended to involve a daily email or phone call from a keyworker and some received weekly updates. One Dad was reassured that their daughter's home, although 100 miles away, kept them informed "every step of the way."

One of the most positive experiences of keeping in touch was in relation to a short break setting. The keyworker used 'WhatsApp' to send photos and quick updates on the day's activities or to consult

Mum about what might lie behind changes in her daughter's mood, behaviour or health. She was the first point of call when they had concerns and she valued this high level of contact.

5. I want a trusting relationship with the keyworker(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.

One mother, who was very unhappy with the way her son was cared for, reported that her suggestions of how to work with him often were not listened to. This young man's condition had deteriorated significantly since going into residential care five years ago. Although his care workers observed to his mother that 'he speaks to you, but he never speaks for us' or would ask 'how did you get him to do that?', they have not been encouraged to learn from her, in spite of her repeated suggestions and offers to train them.

Two parents responding to our survey similarly regretted the lack of a trusting relationship with their children's keyworkers. One referred to a provider's 'paranoia' in a setting where keyworkers were not trusted to communicate directly with parents, but did so covertly by telephone or text. Another wished for a single point of contact, who could provide a more consistent picture of her son's progress day to day (he was being treated in an ATU): "As the shifts changed, they were not always aware of what had happened earlier that day ...different staff would tell the same thing differently."

SEEING MY CHILD REGULARLY

6. My child 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.

Although some children were able to use the telephone, advances in communications

technology have made a very positive impact on their ability to keep in touch with home. Skype and FaceTime were mentioned frequently as an easy way of interacting day-to-day, sometimes with the child initiating a call. These technologies were valued for enabling children to keep in touch with the wider family, siblings, friends and pets and to see the familiar surroundings of home. This worked both ways, helping parents to see their child's living environment and their daily interactions with staff.

Some young people could communicate by text (using symbols) and keyworkers shared photos of daily activities using WhatsApp, Facebook and Wiki Online.¹¹ One Mum thought that the latter had enormous potential, enabling young people, families and carers to share pictures, videos and information securely. Pictures she posted had made the care workers realise that her son could do some things which they had assumed were beyond him.

Staff skills ('not doing social media') and lack of access to Wi-Fi, personal iPads, SmartPhones or other relevant technologies created barriers to communication, which families found very frustrating. One mother responding to our survey summarised the barriers in her son's ATU as follows:

“ No Wi-Fi to use FaceTime on iPad. Expectation that you would leave child there and go home. They did not offer phone contact for us with child. ”

7. Let me visit regularly and help us to make those visits a positive experience for all.

“ The NHS community nurse in charge of my son said if I was finding it difficult to get down to see him, why did I go? The answer is because he is my son and I love him and if I didn't go, no one else would have and he didn't know where he was or any one there. ”

Survey response, son in an ATU

Visits were extremely important to all the parents. For some children, visits require careful planning, so that they are expected (e.g. using a visual timetable) and transitions back to the setting need to be sensitively managed. Many settings provided support workers to enable families to go out together. An ATU in a remote location made a family flat available to make visiting easier.

However there were also challenges to visiting. Some families needed to travel long distances. A parent responding to our survey faced a three-hour round trip to see their child. Another reported that they spent £7000 in petrol over 15 months, visiting their son in an ATU.

Attitudes seemed to present even more of a barrier. One setting only a few miles from the family home (guided by a clinician) suggested to a mother that she should see her young adult son at first for ten minutes after weeks of separation, which she flatly refused, but agreed to half an hour which was also not good. Staff in other settings sometimes turned her away, telling her that he didn't want to see her, and she was always concerned

11. 'Wikis' are accessible, secure and easy to build personal websites which can be used to create multi-media person-centred plans that use pictures, words, video and sound to capture the voice, skills, aspirations and needs of the child or young person

that he would not know that she had come. She described some staff and even some professional attitudes encountered as intimidating.

Parents did not seem aware of the possibility of financial support from the Local Authority for visits and none had received any help with travel costs.

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.

One of the mothers in our focus group spoke of the devastating 'shock of separation' which she had still not got over, five years after her son moved into residential care. She and another Mum were moved to tears when they spoke of their experiences. Clearly the emotion was still raw, even for the mother who was very satisfied with her son's residential special school. Some of the parents consulted said they had experienced mental health problems themselves, due to their children moving away.

Deep emotions could get in the way of communicating effectively, particularly when parents wanted to articulate concerns about their children's care or well-being. One mother was supported by an advocate for eight months which had made a great difference, but the general observation was that advocates for parents were in short supply or not available, due to cuts.

On a more positive note, an ATU which initially resisted parental contact and involvement, later consulted the mother about appointing a family support worker, an idea she strongly supported.

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

“ It's always in the back of your mind when you complain... They've got your daughter there and you're not there. If you are starting not to trust them, it's a very slippery slope. ”

Father

Families explained the difficulties in dealing with incidents involving aggressive behaviour or sudden deteriorations in their child's health or behaviour when living away from home. Experiences contrasted sharply on this front.

One mother described the problem-solving approach taken by her son's school, following an incident of challenging behaviour linked to anxiety about a visit home. Rather than abandoning visits, the school worked with her to identify what was exacerbating his anxiety (a new family home) and gradually built up his visits until he could stay at home for a night again, planning carefully to make his return to school as easy as possible.

By contrast, another mother reported that her visits were sometimes interfered with after she pointed out, for example, out of date milk, poor hygiene or if she asked why care workers were watching television while her son was left alone and unsupported on his bed.

In two cases, parents were clearly distressed about the way their sons (now young adults) were being cared for and the impact they felt this was having on their behaviour, well-being and life chances. Both were deeply concerned by an increase in aggressive and/or self-injurious behaviour, but felt that the more they tried to get involved, the more they were asked to stay away.



CASE STUDY: FINDING THE RIGHT CARE FOR JONATHAN

Jonathan is a sociable young man in his early twenties who loves to spend time with his family and friends, especially his brothers who he looks up to as role models. He has severe learning disabilities and his behaviour can be challenging when he cannot make himself understood or is tired or anxious.

At eleven, he went to a residential special school not far from home. This was in many ways a positive experience, but he was sad to be separated from his family and not able to do the same things as his brothers. He also missed the company of 'more able' peers (in his mother's words). Friday afternoons were hardest, when friends who were not boarding went home.

Jonathan then moved away to a specialist college, living in a care home

nearby. He coped well with more freedom there, but the combination of college and a busy programme of activities organised by the care home left him very tired, contributing to aggressive outbursts on the journey home on Friday afternoons. The Care Home was slow to consult his mother who could have helped them to understand Jonathan's behaviour and adjust his routine. However they did arrange for staff to be trained in Positive Behaviour Support, which helped a lot.

It took a while to establish the level of communication that Jonathan and his mother wanted. They helped Jonathan to overcome his dislike of the telephone so he could call home. There were weekly phone calls with his keyworker and when Skype became available, they used that regularly.

"He's never wanted to leave home, he still clings on".

Jonathan missed home a lot and would visit once every three weeks, with his family visiting on one of the weekends in between. It was hard to balance looking after the rest of the family with seeing Jonathan as much as they wanted, so after three years, they looked for a placement nearer home.

By now a young man, Jonathan came back to supported living not far from home. His first placement broke down as he was lonely and his behaviour deteriorated. When his mother urged the staff there to be trained in Positive Behaviour Support, they said “no, we’re the experts”.

He was moved to another house, nearer to the family home. It is in an isolated location, a taxi ride from the nearest town. The other residents have more challenging behaviours and are not friends with Jonathan. His behaviour deteriorated further and he started self-injuring.

“A wall comes up, because I know too much... If we worked together, we could learn”.

His mother is distraught that he is “looked after by staff who don’t understand him... in totally the wrong environment... and they won’t listen to me.” She tried ‘talking intensively’ with Jonathan to understand what was upsetting him and spent hours in

the lounge, reading his diary. His care workers resented this, telling her “it’s better if parents don’t get involved”. Their manager accused her of trying to ‘pick holes’ in their work. Phone calls and visits were subsequently time-limited and visits confined to her son’s room. The loss of two care workers was blamed on her criticisms and her son’s behaviour.

When she complained to social services, they refused to meet initially, suggesting that it would be better to resolve their differences by email. Jonathan’s mother at this point felt that they were “totally against me”. A new social worker has been appointed and with the support of an independent advocate, they are making progress in rebuilding relationships. She receives a daily email on Jonathan’s activities and has a Skype call with her son most evenings. She also meets the care manager regularly.

Jonathan’s mother still desperately wants a change in setting for her son, but the care manager has warned that this will surely result in a more restrictive placement. Even though he is funded in a full-time placement, she takes him home every weekend and he also visits on a weekday. She fears that Jonathan is learning nothing, that he is unhappy and lonely. Most of all, he lacks a friendship group, which is the most important thing to this young man.

STOP AND THINK!

Our research with family-carers points to a picture of great variability in residential settings, with many positive examples of individuals who listened to parents and were prepared to adapt their practice and go the extra mile for the young people in their care. However, this was against a

prevailing picture of often unsupportive attitudes and inflexible rules around for example, visits or using Skype, creating barriers to family contact.

Assessment and treatment units were singled out for most criticism, for being far away, ‘austere and formidable-looking’; for discouraging families from visiting in the

early weeks following admission, often in traumatic circumstances; for limiting access to phones and the internet; and for failing to keep families informed and involved.

Residential settings for young adults (with the exception of specialist colleges) were criticised more than children’s settings, for failing to appreciate that most parents want to be kept informed and involved in their young person’s life and decision-

making. These young people were in their early twenties, but they ‘lacked capacity’¹² to make key decisions and their parents remained their main advocates.

The key message from our research with families is perhaps best summarised in their own words: “Culture and attitudes make most difference. If these are right, then you can work out the logistics.”

TO CONCLUDE THIS SECTION, THE FAMILY-CARERS ATTENDING THE FOCUS GROUP GENERATED A PRACTICAL CHECKLIST URGING SERVICES AND SERVICE COMMISSIONERS TO ‘STOP AND THINK’ ABOUT HOW THEY HELP FAMILIES TO KEEP IN TOUCH:



12. As defined by the Mental Capacity Act, 2005. See Section Three: The legal framework (sections on SEND Code of Practice 2014 and mental health).

SECTION TWO: WHAT WORKS? LEARNING FROM LOCAL PRACTICE

The main aim of this research was to promote good practice in supporting families to keep in touch with children and young people with learning disabilities who live away from home.

This section begins with case studies from three local settings which show much commitment to keeping families informed, involved and in touch. Two are residential special schools and children's homes, providing 52-week placements; one is a residential specialist college. Key elements of their practice are summarised in a good practice checklist for local settings. These are also relevant to health in-patient settings such as assessment and treatment units (ATUs), where some of the more significant barriers to keeping in touch were

encountered by the families involved in this research. Unfortunately, we struggled to find a case study from an assessment and treatment unit working with young people with learning disabilities.

It was also disappointing that no Local Authorities volunteered their practice, as the key agency responsible for making residential placements and for promoting and safeguarding the welfare of children and young people living away from home. The latter part of this section looks briefly at the role of local authorities, based on their statutory duties (set out in more detail in Section Three), concluding with a good practice checklist for local authorities and health commissioners.

CASE STUDIES FROM THREE LOCAL SETTINGS

CASE STUDY 1

The Royal College Manchester is a specialist college, providing education and residential care to young people aged 19-25 years with complex learning disabilities and communication needs. It is part of the Seashell Trust, which also runs a residential special school and a short breaks service.

Supporting the transition to college

The College works closely with families and young people who are thinking about joining them, seeking to involve young people in the decision to apply and supporting their transition. Most young people visit around three times before they start, including a half-day assessment and an overnight stay. Students are given a record of their visits, in an accessible format with lots of photos.

The Trust's Family Link Worker is the key point of contact throughout this process and beyond. They plan with the family to help their young person to settle in, for example, some want weekly visits home at first. Bedrooms are decorated with photos and items from home. If students are homesick, sensory 'memory boxes' may be created with familiar things such as music, photos, a scented cushion, an old toy.

Keeping families informed

One of the early conversations with families is to agree how they would like to be updated on their young person's life at College. They share paper records - a home-college book and student diaries with lots of photos - and many parents receive a weekly email or a nightly phone call from a keyworker. Families are asked about how

they would like to be informed about behavioural incidents or accidents, which are rigorously recorded. Some families want to be contacted every time, while others prefer occasional updates. This is kept under review, recognising that it takes time to establish right level of communication for each family around sensitive issues.

Person-centred planning is used to ensure that students can keep in touch with people who are important to them. This includes gathering 'social circle' information. Students are encouraged to build friendships and College graduates are sometimes paired by Local Authorities in future placements.

The Trust has a network of volunteer befrienders who visit regularly to build relationships with young people who would not otherwise be visited, although this is rarely needed.

Video technology

"We love video technology... Skype has been wonderful!"

The College has an assistive technologist who ensures that the College takes advantage of new technologies to enable students' communication. Skype is used widely to keep in touch with families, as well as FaceTime and less commonly, phone calls, emails and texts. The College has a bank of iPads, accessible in every house (many students have their own iPad). E-safety training is regularly provided for staff and students.

Students' voice

"Promoting communication is at the heart of what we do."

The College has a 'Learner Voice Coordinator' who supports and challenges colleagues to involve young

people in decision-making. Many of their students have profound and multiple learning difficulties and little verbal communication. Learning to read their behaviour and responses, logging this and sharing this information across the team is integral to the way they work. Staff are expected to act as advocates for young people and occasionally independent advocates are involved to help with decision-making or if a young person does not have the support of their family.

Visits

The College has an Open Door Policy, so parents can visit at any time. There is a family flat which can be booked. Each student has a calendar in an accessible format, showing key dates such as family visits and holidays.

The College and the Seashell Trust organise family events (some targeted at siblings) throughout the year, providing opportunities to get to know the staff and other families, and to learn about topical issues such as changes in legislation or planning for the transition beyond College. Parents/carers can join a closed Facebook page, providing a forum for information-sharing, advice and support.

Delivering positive behaviour support in partnership with the family

Jack is 19 years old and boards at the Royal College Manchester. He has three siblings and visits his family every fortnight. He has a diagnosis of Down syndrome, with severe learning disabilities, non-verbal communication and behaviour which can be challenging.

All staff in the Seashell Trust are trained in positive behaviour support (PBS). They work proactively with families to ensure a consistent approach is taken at

home and in College. PBS is embedded in each student's integrated support plan, which explains their likes and dislikes, cues and triggers and what may underlie their behaviour. Strategies – proactive, active and reactive – are set out which minimise the need for restrictive interventions. Jack has a sensory profile, which includes wearing a weighted jacket to help him cope during transition times.

From the beginning, Jack's parents have

been closely involved in implementing his programme – attending multi-disciplinary meetings, contributing to his integrated support plan and linking regularly with the behaviour support coordinator.

Training has been provided for Jack's mother, his siblings and their partners, all of whom support him at times, to enable a consistent approach and helping them to understand his behaviour better and how best to support him.

CASE STUDY 2

Sunfield is an independent residential special school and children's home in the West Midlands, for children aged 6 – 19 years with complex needs, including Autism and Pathological Demand Avoidance Syndrome. Most students have severe learning disabilities and around 80% have little or no verbal communication.

Working in partnership with families is central to their approach, led by a Family Services Coordinator. There is also a Referrals, Admissions and Transition Team who work closely with each young person and their family when they start and when it is time to plan for their next move.

Before a child joins the school, staff visit the family home to share a file of information, which explains arrangements for visits, phone and Skype contact and independent advocacy. Families fill in a 'family contact contract' which allows them to specify how they would like to be kept updated on what their child has been doing, for example, through daily or weekly phone calls or emails from a keyworker. There

are regular newsletters from the school and individual houses, full of photos and news of activities, events and achievements.

The school is committed to "open and honest communication that is both supportive and challenging" (values statement on website). If an incident occurs, a member of the house staff team phones the family on the same day and ensures that they can speak to their child as soon as possible.

The school has a contract with Voice advocacy to visit once a fortnight, meeting young people in their houses – getting to know them, providing a vehicle to raise any concerns about their care and representing their interests. Sometimes they support students at review meetings. The same advocates visit regularly and are skilled in non-verbal communication.

Each house has a phone line, which students and families can use whenever they want. There is a dedicated room with Skype facilities in the main house, used extensively by students with communication difficulties. They plan to introduce an iPad/tablet to allow Skype

to be used in each house once they have resolved e-safety concerns.¹³

The school operates an 'open door' visiting policy, so families can book in to visit whenever they want. There is a private visiting area where families can spend time together and two self-contained family flats. They host sibling activity days and residential weekends to give insights into life at Sunfield (many children are on 52-week placements), encouraging siblings to stay involved and to build friendships with each other. They have produced two Sibling Information Booklets, aimed at older and younger children. Where

appropriate, older siblings can attend review meetings.

Families are regularly consulted and have the opportunity to influence the school's policies and direction through involvement in their Family Forum (represented on the school's Advisory Council). This meets once a term and includes parents, siblings and grandparents. It prompted the introduction of Skype and various training and activity days. There are also regular family surveys.

CASE STUDY 3

The Loddon School is a residential special school and children's home for up to 30 children with severe learning disabilities, autism and behaviour that challenges, aged 8 to 19 years. All are on 52-week placements, living in small house groups, supported by dedicated keyworker teams. They take a highly individualised approach to working with the children in their care and their families.

Settling in

When they know that a child will be joining, they usually visit to meet the child and their family in their own home, with frequent phone contact through the transition period. Children's rooms can be decorated with photos from home, their own bedding and favourite

belongings.

They work hard at building positive relationships with families, recognising that parents have their own needs and that many have previously experienced a succession of placement breakdowns.

Keeping families informed

Parents are given an information pack which sets out policies for seeking consent (e.g. for medical treatment) and for informing them about any changes in their child's care. The school agrees with parents how they would like to be kept updated. Typically this involves regular phone calls or emails, trying to ensure that families are contacted consistently by the same one or two key people.

All incidents are recorded and reviewed every week. Families are informed about incidents in whichever way they want: an

13. Mencap are involved in the 'Inclusion Europe' SafeSurfing project to promote e-safety for people with learning disabilities. See www.mencap.org.uk/safesurfing. For resources on cyber-bullying, see www.mencap.org.uk/get-involved/campaigns/what-we-campaign-about/children-and-young-people/anti-bullying-week/resources and www.anti-bullyingalliance.org.uk/resources/cyberbullying/cyberbullying-and-sendisability

immediate phone call, a weekly record of incidents or monthly updates. This information is also shared with social workers.

Children create a card to send home every week (the school has a vibrant art department) and they phone home every week. They produce their own weekly updates for parents, using templates which allow them to put together their own version of what they've been up to, using lots of photos. Some use Skype, but this is not used widely.

The school also produces a parents' newsletter twice a term, full of photos and news of children's activities and achievements. They are currently developing a 'Student Blogs' website to enable parents to access online updates and information about their child's progress, and giving them another way of having a dialogue with staff.

Involving families

At the Loddon School, all students use PECs.¹⁴ Individual communication books are prepared and shared with home. These are supplemented with 'home visit' books, with families supplying images of, for example, Mum, Dad, siblings, home, football, the beach, pets, so that children can be prepared for visits and know what is going to happen next. For example, one young man was going to take a train and a ferry to visit his sibling abroad, so images were used to explain his journey, ending with coming back to school.

'Social stories' are developed to help children to know about significant changes at home: the birth of a

sibling, moving house, a marriage or bereavement. These simple stories use words, symbols and images to explain an event, how they may feel and what happens next. One young man had recently lost his Dad, so his story explained that he would not see Dad again, that he would feel sad, but that the rest of his family were still there and would spend time with him and be happy again.

Stories are also used to prepare children for new experiences and to influence their behaviour. Examples included preparing a young woman for an operation and hospital stay; preparing a young man to visit the Mosque for the first time; getting a child to sleep in his own bed on a visit home, rather than his Mum's bed. They supported one family to rebuild their son's relationship with his little sister, who had become scared of him. They used social stories to help him to understand how to behave and play with her and ensured that the time they spent together was a positive experience. They were delighted to see the two siblings hugging and holding hands on a recent visit.

Visits

Families are encouraged to visit regularly and there are several safe, family-friendly areas on site where they can spend time together, with support from a keyworker if they want. They can use the school's facilities, such as the pool and sensory room and adventure play areas.

The school hosts regular activity days, some with cultural themes, for example, with families preparing special ethnic dishes. Staff join in, providing an informal opportunity to get to know

14. Picture Exchange Communication System – a widely-used system which uses cards with pictures and symbols on them to help children communicate.

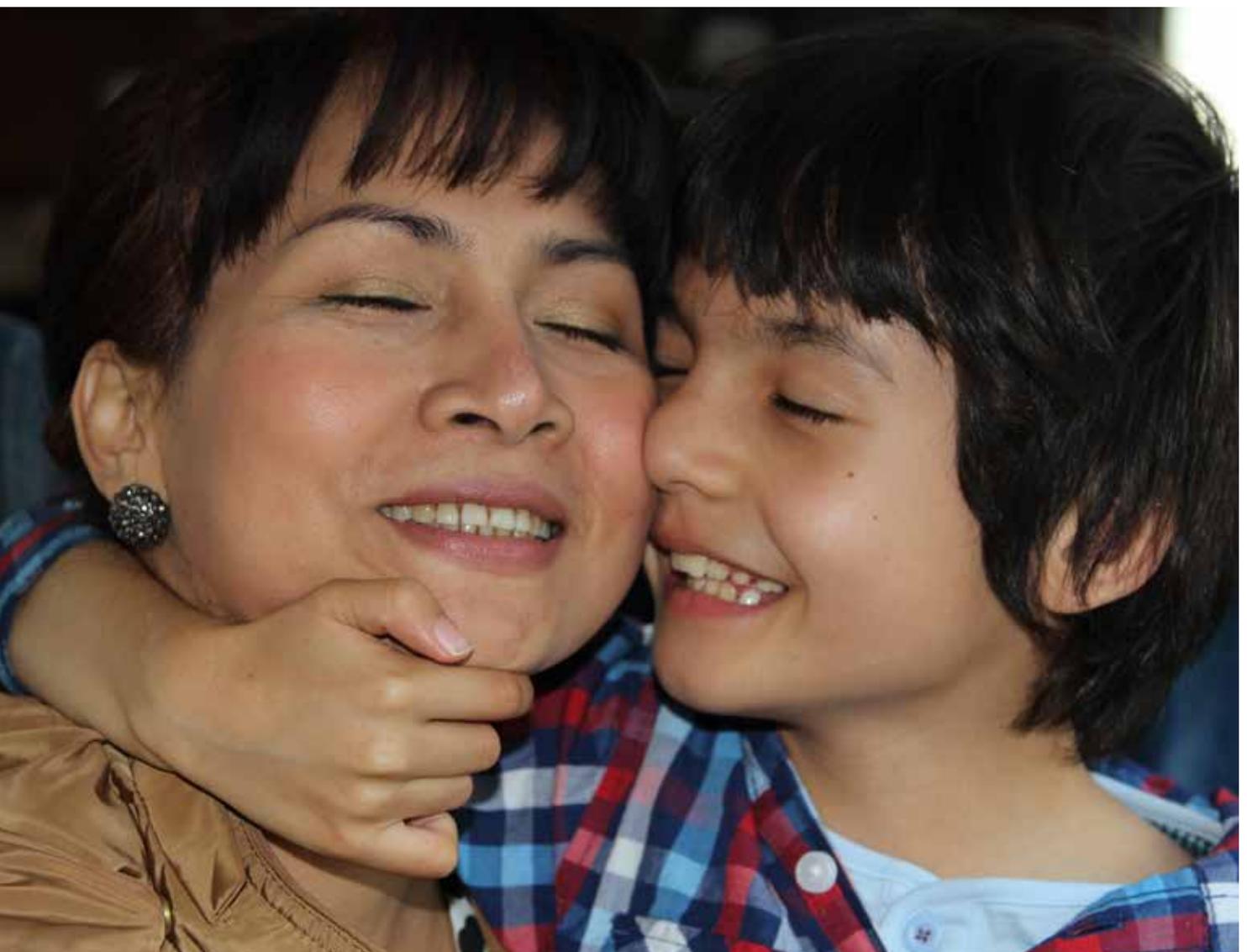
families and for parents to ask them questions. Parents are also encouraged to attend special assemblies and can visit the school whenever they want.

Monitoring and promoting family contact

The school logs all contact with families (number of phone calls, emails, visits) and reports on this in each child's Looked After Child review, also analysing the impact on behaviour. If contact with home dwindles, they encourage parents

to be more engaged and sometimes ask to involve the social worker.

They go to great lengths to facilitate visits home: for children from the other side of the country, they have met parents half-way to reduce their journey time and accompanied children on overnight visits. They work flexibly to allow children to be included in significant family events, for example, accompanying a child to a wedding reception.





GOOD PRACTICE CHECKLIST FOR LOCAL SETTINGS

This twenty-point checklist draws together key elements of ‘good practice’ emerging from the case studies. It corresponds closely with family-carers’ feedback (described on Section One) on what works well and the sort of practice they would like to see.

Although based on the experience of residential special schools and children’s homes and a specialist college, the great majority of this practice is relevant to all

types of residential setting for children and young people.

We hope the checklist will provide a useful starting point for managers to review their policies and practice. They may also find it helpful to use the graphics generated by family carers (see Section One) as a basis for discussion with staff groups, to explore attitudes and approaches.

Parent-carers may also wish to use these resources to prompt improvements in practice

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

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
-
- 13** Invite families to join in activity days, information sessions and training. Provide opportunities for them to get to know each other and staff
-
- 14** For young people who have no-one to visit them, find a suitable befriender and advocate

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
-
- 16** Use secure websites e.g. Wiki Online to facilitate information-sharing and an on-going dialogue between staff and families
-
- 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
-
- 18** Have a staff member who is responsible for championing the use of new technologies to aid communication for children and young people

ADVOCACY

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

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.

GOOD PRACTICE CHECKLIST FOR LOCAL AUTHORITIES AND HEALTH COMMISSIONERS

Local Authorities have important duties towards disabled children and young people in residential placements, as set out in Section 3: The legal framework. These include:

- A general duty to safeguard and promote the welfare of disabled children (as ‘children in need’) in their area and to promote their upbringing by their families
- Additional duties in respect of children ‘looked after’ by the Local Authority, including promoting contact between the child and their parents/carers (unless at risk of harm) and enabling parents to retain their responsibilities and to remain closely involved, even if their child has to live away from home
- Securing placements near home for children with special educational needs and disabilities or where a distant placement is needed, providing help with travel costs
- Promoting and supporting contact between families and children living in residential settings for 3 months or more; and regularly visiting all such children
- Involving children, young people and parents/carers in key reviews and decision-making, providing the necessary information and support to enable their participation¹⁵
- Parent-carers may also wish to use these resources to prompt improvements in practice

As the lead agency responsible for commissioning, maintaining and reviewing residential placements for disabled children and young people, Local Authorities can set high expectations about how keeping in touch with home and family should be supported by local settings.

Health commissioners also have an important role to play, through the joint commissioning of services (including residential placements) for children and young people with complex needs, and commissioning mental health in-patient services in line with the positive principles set out in the National Service Model.¹⁶

Unfortunately, no Local Authorities or Transforming Care Partnerships responded to our case study requests; and given the

limited scope of this research, we cannot comment on how their practice measures up to statutory expectations. However the accounts we heard from family-carers (see Section 1) as well as residential settings point to a lack of engagement by local authorities, once children and young people have settled into placements. This an area worthy of further research.

This seven-point checklist is based on what the families of children and young people in residential placements told us they want and need, to help them to stay in touch, informed and involved, while their child or young person is living away from home. It sets out key questions for local authorities and health commissioners to ask themselves and to ask of local settings, to promote good practice.

15. See Section Three. These duties arise from the Children Act 1989 & guidance (Vol. 2: Care planning, placement and case review); the SEND Code of Practice 2014 and the Visiting Regulations 2011.

16. ADASS, LGA and NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

WHAT FAMILIES WANT	KEY QUESTIONS FOR LOCAL AUTHORITIES AND HEALTH COMMISSIONERS
<p>1.</p> <p>Regular visits, planned around the needs of the young person and family</p>	<p>Are families made aware of their entitlement to help with travel/transport costs, where distant placements are made?</p> <p>Do placement plans set out clear expectations for regular visits by family and/or other people closest to the child or young person? Does placement funding provide for support for visits?</p> <p>Do regular reviews look at how often the child has been visited? What action is taken if contact is dwindling?</p> <p>What arrangements are in place to provide regular visits from a consistent person for young people whose families do not visit e.g. befriending or advocacy?</p> <p>Are settings' policies supportive of regular visits by family and/or significant others?</p>
<p>2.</p> <p>A child-and family-centred plan for "keeping in touch" is agreed at the outset and regularly reviewed</p>	<p>Do settings ask children, young people and their families how they would like to keep in touch and agree arrangements for regular:</p> <ul style="list-style-type: none"> • calls (or as appropriate) with their child or young person? • updates on their activities, health and well-being and any incidents from a consistent staff member? <p>Are 'keeping in touch' arrangements agreed in a written plan and reviewed regularly to ensure the right level of communication?</p>
<p>3.</p> <p>Families involved in transition planning, at the point of admission or before</p>	<p>Do settings encourage family involvement to support a smooth transition to a new residential placement? Including:</p> <ul style="list-style-type: none"> • visits by the child/young person and their family • learning from the family and child/young person about their interests, how they communicate, behaviour, cultural identity and anything else that matters to them. <p>Are key plans shared with the setting in good time e.g. Communication Passport, Education, Health and Care Plan, Hospital Passport, Health Action Plan and any other relevant information?</p> <p>Is training e.g. in Positive Behaviour Support provided to enable consistent, evidence-based approaches to be used?</p>
<p>4.</p> <p>Supporting children to "feel at home"</p>	<p>Do settings allow children/young people and families to decorate their own living space with e.g. favourite belongings, pictures of home and significant people in young person's life?</p> <p>How do settings reflect children and young people's cultural identity?</p>

WHAT FAMILIES WANT	KEY QUESTIONS FOR LOCAL AUTHORITIES AND HEALTH COMMISSIONERS
<p>5. Making the most of communications technologies</p>	<p>Are audio-visual technologies such as Skype used by residential settings to facilitate communication, especially for non-verbal children? If not, what action is needed to promote this – e.g. training in e-safety, skills development, software licenses, help with purchasing devices?</p> <p>How can Transforming Care Partnerships/Local Authorities/health commissioners promote the use of new technologies to facilitate communication between the child and their family or significant others, and between the setting and the family?</p>
<p>6. Access to advocacy and skills in non-verbal communication</p>	<p>Do independent advocates regularly visit all residential settings where children in full-time placements are living?</p> <p>Do all children in 52-week placements, children placed out of area and children with little family contact have regular access to independent advocacy (including those who are not looked after)?</p> <p>Are Local Authority visitors, independent reviewing officers, social workers and independent advocates skilled in non-verbal communication?</p>
<p>7. Listening to parents' concerns, supporting them and intervening when trust breaks down</p>	<p>Is feedback regularly sought from families of children and young people in residential settings about their satisfaction with their child/young person's care; and how well they are supported and informed by the local authority?</p> <p>Does family feedback (on residential placements) inform service planning and commissioning?</p> <p>What support is available to parent-carers when relationships with settings become difficult and trust breaks down? Are advocates available? Are parents informed of support available from voluntary organisations?</p> <p>Are protocols in place for resolving concerns and complaints about residential settings, ensuring that the child or young person's best interests remain paramount?</p>

SECTION THREE: THE LEGAL FRAMEWORK

The legal framework around keeping in touch when a child or young person is in a residential placement is complex. This section provides a brief overview of key rights, duties and expectations about how families, children and young people in residential placements should be supported to keep in touch, as well as how they should be involved in decision-making.

Given the resource constraints for this project, our legal review focused on England, much of the legislation is also

relevant to Wales. International human rights form the bedrock of the legal framework and clearly, are relevant across national boundaries.

This section is long and fairly detailed, so we suggest that readers may want to dip into those parts that are relevant, guided by the table below. This section concludes with links to many useful resources which are available freely online, which offer detailed, authoritative guidance on aspects of the legal framework.

	Legislation / statutory guidance	Which children and young people?	Which settings and agencies?
3.1	Human rights legislation: UN Convention on Rights of the Child UN Convention on the Rights of Persons with Disabilities European Convention on Human Rights	All, with additional duties towards children and young people with disabilities	All
3.2	Children Act 1989: duties towards disabled children as 'children in need'; and 'accommodated children'	Disabled children Children living in residential settings for more than 3 months	Local Authorities
3.3	The Visiting Regulations 2011 (under the Children Act 1989)	Children living in residential settings for more than 3 months	Local Authorities Residential settings
3.4	Children Act 1989: duties towards 'looked after children' living away from home	Children looked after by the Local Authority and living away from home	Local Authorities
3.5	NICE Quality Standards for the health and well-being of looked after children	Looked after children in health in-patient units	Health in-patient units

3.6	Children and Families Act 2014 and the SEND Code of Practice 2014 Involvement in decision-making Residential placements	Children and young people aged 16+ with an EHC Plans (formerly, SEN Statements)	Health, education, social care All settings
3.7	Residential Special Schools and Children's Homes regulations and standards	Children in these settings	Residential Special Schools Children's Homes
3.8	Transforming Care, Care & Treatment Reviews and the National Service Model	Children and young people in mental health in-patient settings	Transforming Care Partnerships In-patient settings
3.9	Mental Health Act 1983 Code of Practice Involving families in decision-making Consent Decision-making for young adults Nearest relatives Local authority duties	Children and young people in ATUs and other mental health in-patient settings	Transforming Care Partnerships In-patient settings Local authorities

3.1 HUMAN RIGHTS LEGISLATION

Human rights legislation provides a framework for commissioners (including Local Authorities and health commissioners) and providers (local settings and the organisations that run them) to deliver the best possible outcomes for people using their services. They are expected to put international human rights principles into practice and to ensure that individual rights are protected and promoted.

The **UN Convention on Rights of the Child (UNCRC)** was ratified by the United Kingdom in 1991. These rights apply to all children under the age of 18 years.

- Article 7 sets out the right of a child 'to know and be cared for by his or her parents'.

- Article 9 sets out children's right to live with their parents (unless at risk of harm). Where children must live away from home, they have the right 'to maintain personal relations and direct contact with both parents on a regular basis', unless this is not in their best interests.
- Article 20 specifies that where children have to live away from their family, 'due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background'.
- Article 23 promotes the rights of disabled children to 'enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and

facilitate the child's active participation in the community'.

The **UN Convention on the Rights of Persons with Disabilities (UNCRPD)** was ratified by the United Kingdom in 2009. It aims to ensure that disabled people's human rights are put into practice, removing barriers to dignity, inclusion and participation and setting standards for how Government and public bodies should ensure that disabled people's rights are protected and promoted.

- Article 9 (accessibility) expects States to promote access to new information and communications technologies (ICT) including use of the internet; and promote the development and distribution of accessible, affordable technologies.
- Article 19 sets out the rights of disabled people to live in the community, to choose where they live and with whom; and to be provided with support to make this possible.
- Article 23 deals with respect for home and family. Children with disabilities have equal rights to family life and should not be separated from their parents, unless that it is in their best interests; in no case should a child be separated from parents on the basis of a disability.

The **European Convention on Human Rights (ECHR)** was brought into UK Law by the **Human Rights Act 1998**. Public bodies (including Local Authorities and health commissioners) must act in a way which is compatible with these rights and are required to respect and protect them. Providers (local settings and the organisations which run them) have a duty to respect and protect human rights.

Article 8 states that 'everyone has the right to respect for his private and family life, his home and his correspondence'.

3.2 THE CHILDREN ACT 1989: DUTIES TOWARDS DISABLED CHILDREN AS 'CHILDREN IN NEED' AND 'ACCOMMODATED CHILDREN'

Disabled children are 'children in need' under the Children Act 1989. Local Authorities have a duty to assess their needs and provide support considered necessary, based on this assessment. Local Authorities have a duty to safeguard and promote the welfare of 'children in need' in their area and to promote their upbringing by their families.¹⁷

If a 'child in need' is placed in accommodation in another area, he or she remains the responsibility of the placing authority.¹⁸

The responsible Children's Services department (usually, where the child's family live) should be notified if a child is accommodated for at least three months; notifications must be made by the placing agency (health or the local education authority).¹⁹ Care homes and independent hospitals are also required to notify the local authority in which they are situated, if they accommodate children for three or more months.²⁰

Local Authorities should promote contact between families and children living apart because they have been 'accommodated'.²¹ To achieve this, Local Authorities may provide:

- Advice, guidance and counselling;
- Services to enable the child to visit, or be visited by, members of their family;
- Assistance to enable the child and

17. Section 17(1-5) of The Children Act 1989

18. Section 105(6) of The Children Act 1989

19. Section 85 of the Children Act 1989

20. Section 86 of The Children Act 1989

21. Schedule 2(8A) of The Children Act 1989

members of the family to have a holiday together.

3.3 THE VISITING REGULATIONS, 2011

New regulations were introduced in England and Wales in 2011 to strengthen Local Authorities' responsibilities towards children living for more than 3 months in residential settings such as special schools, hospitals or care homes. The responsible Local Authority (usually the one making the placement) must 'make arrangements for the child to be visited by their representative' to advise and assist in their duty to determine whether that child's welfare is adequately safeguarded and promoted.

Statutory guidance to clarify the 'Visiting Regulations' was promised in 2011 and published that year in Wales. The English guidance is still awaited and could be valuable in driving improvements in Local Authority practice. Key elements of the Welsh Assembly Guidance²³ which we hope to see replicated in England include:

- Most children in residential placements for more than three months should have had a holistic, multi-agency assessment of their needs. The resulting plan should consider how to maintain and improve the child's relationships with their parents and others caring for him/her.
- The placement plan should specify arrangements for visits by the local authority and the family. It should clearly state contact arrangements with parents, family members and significant others. For many children with communication difficulties, 'face-to-face contact will be essential'.

- Children living away from home will benefit from contact with parents, siblings and members of the wider family. It is important to find out which significant relationships should be promoted.²²
- Often families will require support and encouragement to maintain contact with their child, perhaps with support from a voluntary organisation. Advice and counselling services can be provided by the Local Authority as well as practical services, such as help with transport costs and costs of a family holiday.

3.4 CHILDREN ACT 1989: DUTIES TOWARDS 'LOOKED AFTER CHILDREN' LIVING AWAY FROM HOME

Where Local Authorities are involved in decisions to place a child away from home, they should consider whether that child's welfare would be better safeguarded and promoted if 'looked after' under the Children Act 1989. This brings into play stronger requirements including more frequent visits and reviews, the involvement of an Independent Reviewing Officer and a clearer right to independent advocacy. Around three-quarters of children in 52-week placements in residential special schools are looked after,²⁴ most of them on a voluntary basis in agreement with their family.

Statutory guidance²⁵ under the Children Act 1989 clarifies the responsibilities of Local Authorities and residential settings towards looked after children. Local Authorities must endeavour to promote contact between a looked after child and parents/carers, unless not practicable or consistent with protecting the child's welfare. Good practice principles set out in the guidance

22. Department for Education (2011) Explanatory Memorandum to the visits to children in long-term residential care regulations. <http://bit.ly/1UL96wi>

23. Welsh Assembly Government Circular (2011) The Visits to Children in Long-term Residential Care Regulations 2011 Statutory guidance on how to safeguard and promote the welfare of children in long-term residential care. <http://bit.ly/1M1Y3r7>

24. This data is not collected nationally, so this estimate draws on the best available data, published by the Regional Partnerships in 2008: Analysis of Out of Authority Placements, July 2008

25. Department for Education (2015) The Children Act 1989 guidance and regulations Volume 2: care planning, placement and case review.

include (p.13, para. 1.6):

- Parents should be expected and enabled to retain their responsibilities and to remain as closely involved as is consistent with their child's welfare, even if that child cannot live at home.
- If children have to live apart from their family, they and their parents should be given adequate information and helped to consider alternatives and contribute to the making of an informed choice about the most appropriate form of care.
- Continuity of relationships is important and attachments should be respected, sustained and developed.
- A change of home, carer, social worker or school almost always carries some risk to a child's development and welfare.

3.5 NICE QUALITY STANDARDS FOR THE HEALTH AND WELLBEING OF LOOKED AFTER CHILDREN AND YOUNG PEOPLE

The National Institute for Health and Care Excellence (NICE) developed quality standards for the health and wellbeing of looked-after children and young people. These apply to settings and services working with looked-after children and care leavers, defining best practice and priority areas for improving the quality of services.

Quality Statement 4 focuses on "Support to explore and make sense of identity and relationships".²⁶ This states that: "Children and young people have needs and preferences for contact with people they value, for example siblings, who may be an important part of their identity. Good contact management is important for promoting a sense of belonging, positive self-esteem and emotional wellbeing."

The NICE Quality Standards also specify what is expected of different agencies

and institutions involved in children's care to ensure that standards are met. Local Authorities, commissioning bodies, organisations providing care, social care, education and healthcare staff should all "offer looked-after children and young people on-going opportunities...to maintain contact with people they value, if this is desired and in their best interests."

3.6 THE CHILDREN AND FAMILIES ACT 2014 AND THE SEND CODE OF PRACTICE 2014

Involving children, young people and parents/carers in decision-making

Local Authority and health bodies' duties towards children with special educational needs and disabilities (SEND) are set out in the SEND Code of Practice 2014.²⁷ A key principle underpinning this is the need to involve children, young people and parents in decision-making, providing information and support for them to be able to participate meaningfully (p.19, para.1.1).

The Children and Families Act 2014 greatly strengthened the rights of young people aged 16 and over to be directly involved in decision-making. The SEND Code of Practice states that: "As young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than to their parents. Parents, or other family members, can continue to support young people in making decisions, or act on their behalf, provided that the young person is happy for them to do so, and it is likely that parents will remain closely involved in the great majority of cases." (p.127, para.8.15)

The Code also specifies that 'Local Authorities, schools, colleges, health

26. NICE (2013) Looked-after children and young people.

27. Department for Education and Department of Health (2014) Special educational needs and disability code of practice: 0 to 25 years.

services and other agencies should continue to involve parents in discussions about the young person's future' (p.127, para.8.17) particularly while the young person is 16 and 17 years old.

Local Authorities should also ensure that young people who need help to ensure their views are listened to have access to 'an independent skilled supporter'. (p.128, para.8.20)

If a young person does not have the mental capacity to make a particular decision, a representative will be involved on their behalf, usually their parent. If a Deputy has been appointed (with power of attorney) by the Court of Protection, they will be involved, again, usually the young person's parent.²⁸ However the Code stresses that it is important to help young people to be involved in decision-making wherever possible.

Residential placements

The SEND Code of Practice emphasises the desirability of local placements, wherever possible. Local Authorities and health commissioners are expected to work together to consider how they will reduce out-of-area placements, and encouraged to consider regional commissioning.

Where a residential placement is needed to meet a child's special educational needs, 'so far as reasonably practicable, those placing the child or young person should try to secure a placement that is near to the child's home... they should ensure they have full regard for the views, wishes and feelings of the child or young person and their families about the placement. Where the Local Authority names a residential provision at some distance from the family's home the Local Authority must provide reasonable transport or travel assistance. The latter might be reimbursement of public transport costs, petrol costs

or provision of a travel pass' (p.214, para.10.29).

3.7 NATIONAL MINIMUM STANDARDS FOR RESIDENTIAL SPECIAL SCHOOLS AND THE CHILDREN'S HOMES QUALITY STANDARDS

Residential special schools

New minimum standards for residential special schools in England came into force in April 2015.²⁹ Schools are inspected against these standards to ensure that they are meeting their legal duty to safeguard and promote the welfare of children boarding there.

Standard 4 covers contact with parents/carers. This states: "Children can contact their parents/ carers and families in private and schools facilitate this where necessary (monitoring permitted, where appropriate)... Communication aids should be available for children who need them."

Standard 10 is about activities and free time. This expects that: "Children are encouraged and enabled to make and sustain friendships with children outside the school, which may involve friends visiting the school and reciprocal arrangements to visit friends' homes."

Children's Homes Regulations and Quality Standards³⁰

The new Children's Homes Quality Standards apply to all Children's Homes, including residential special schools which are dual-registered because they offer 52-week placements.

Regulation 5(a) requires the registered person (responsible for running the Children's Home) to seek to involve the Local Authority placing a looked-after child, usually by working with their social worker. Where children are not looked after, "a close working relationship is essential with

28. The Mental Capacity Act 2005 applies. Annex 1 of the SEND Code of Practice (2014) explains in more detail. See also overview of mental health legislation in this section.

29. Department for Education (2015) Residential special schools: National minimum standards.

30. Department for Education (2015) Guide to the Children's Homes Regulations including the quality standards

those with parental responsibility for them, usually their parents or other carers.”

For looked after children, the Local Authority should record the level and type of family involvement expected in their care plan. For children who are not looked-after, “the home should frequently seek the views and involvement of parents/carers and others with a significant relationship to the child as relevant persons in that child’s care.”

The ‘Positive Relationships’ standard expects that “Children should be supported to understand how to build friendships with other children. They should be able to spend time with their friends in the local community, in their home area, and by having friends visit them at the home, in line with the child’s plans, age and understanding”.

The ‘Care Planning Standard’ includes a section on contact with home, which states that:

- “It will be in the interests of the majority of looked-after children to maintain contact with their families and friends... arrangements for contact and any contact details (telephone numbers etc.) must be included in the placement plan agreed between the registered person and the child’s placing authority and updated regularly.”
- “Children’s homes have a duty to provide access to a telephone that children can use privately... This can include the provision of a mobile phone where appropriate and safe for the child, as long as an alternative is in place for the child to make telephone calls in private if their personal mobile phone is lost, out of credit or broken.”
- “Appropriate forms of contact should

be promoted and facilitated for each child, including where appropriate visits to the child in the home; visits by the child to relatives and/or friends; letters, emails and texts; use of social media and other forms of contact via the internet.”

3.8 TRANSFORMING CARE, CARE & TREATMENT REVIEWS (CTRS) AND THE NATIONAL SERVICE MODEL

Following the shocking abuse of in-patients with learning disabilities at Winterbourne View³¹ uncovered by a Panorama investigation in 2011, a national programme of reform (‘Transforming Care’) was launched to reduce to long-term stays in hospitals and mental health units for people with learning disabilities, autism and challenging behaviour. Transforming Care establishes the clear principle that: “The norm should always be that children, young people and adults live in their own homes with the support they need for independent living within a safe environment. People with challenging behaviour benefit from personalised care, not large congregate settings.”³²

To drive progress and to clarify what local commissioners should be aiming for, a National Service Model³³ was published in 2015, which local areas must implement over the next three years. Family carers were involved in its development and the importance of supporting and involving families is emphasised.

One of the ‘golden threads’ running through this model concerns choice and control. It highlights the “need to ‘shift the balance of power’ away from more paternalistic services which are ‘doing to’ rather than ‘working with’ people, to a recognition that individuals, their families and carers are experts in their own lives and are able to make informed decisions about the support

31. A brief history of the scandal & Government response is provided here: <http://bit.ly/1U8Ke4K>

32. Department of Health (2012) Transforming Care: A national response to Winterbourne View Hospital. Available at: <http://bit.ly/1qvKbAQ>

33. ADASS, LGA and NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

they receive... People should be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interests involving them as much as possible and those who know them well.”

A set of nine core principles are at the heart of the National Service Model, described as the reasonable expectations of someone who might use services. Many of these are relevant:

- Principle 1: “I have a good and meaningful everyday life” includes: “the opportunity to develop and maintain good relationships with people. Commissioners should be mindful of the importance of relationships to keep people safe and well, and should therefore seek to offer good support to families/ carers, friends and others.”
- Principle 3: “I have choice and control over how my health and care needs are met” highlights the need for individuals to receive information in an accessible format and support to help them communicate. “Individuals, and where appropriate families/carers, should be integral partners in care and support planning discussions.” People should have access to independent advocacy to support decision-making, particularly for key decisions.
- Principle 9: “If I am admitted for assessment and treatment in a hospital setting because my health needs can’t be met in the community, it is high-quality and I don’t stay there longer than I need to”. This further specifies that “Services should seek to minimise patients’ length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment with measurable outcomes. Hospitals should not become de facto homes; discharge planning should start from the point of admission - or earlier for a planned admission. Care and treatment should

be regularly reviewed, in line with NHS England Care and Treatment Review guidance... Services should be as close to home as possible and provide care and treatment in the least restrictive setting... at any stage in hospital, should there be concerns about care and treatment, the person themselves, their family, advocate, commissioner or clinical team have a ‘right to request’ a CTR.”

The useful information list which concludes this section provides further information on Care and Treatment Reviews.

3.9 MENTAL HEALTH ACT 1983 CODE OF PRACTICE

The legislation around mental health is particularly complex. A Code of Practice sets out the requirements on providers to support families to be informed, involved and in touch with their child or young person who is being assessed or treated. These are summarised under six headings:

- 1. Involving families in decision-making**
- 2. Consent**
- 3. Decision-making in adulthood and ‘Deputyship’**
- 4. Nearest relatives**
- 5. Visiting children and young people in mental health in-patient settings**
- 6. Local Authorities’ duties towards children living in mental health settings for 3 months or more**

Excellent mental health legal briefings available online, links are provided at the end of this section.

1. Involving families in decision-making

The Mental Health Act 1983 Code of Practice sets out five over-arching principles ‘which should always be considered when making decisions in relation to care, support or treatment provided under the Act’. Two of these

establish clear expectations around listening to families and involving them in decision-making:

- **Empowerment and involvement:** Patients should be fully involved in decisions about care, support and treatment. The views of families, carers and others, if appropriate, should be fully considered when taking decisions. Where decisions are taken which are contradictory to views expressed, professionals should explain the reasons for this.
- **Respect and dignity:** Patients, their families and carers should be treated with respect and dignity and listened to by professionals.

The need to involve families is reiterated at many points in the Code, including:

- Chapter 19 (Children and Young People): 'Those with parental responsibility have a central role in relation to decisions about the admission and treatment of their child' (p.170, para.19.6).
- Chapter 20 (Patients with learning disabilities and autistic spectrum disorders) cautions professionals involved in assessment and treatment against 'failing to consult or fully listen to carers who, as 'experts by experience', can play an important role in providing relevant information about the person's past, or about effective communication methods'; but also warns against 'over-reliance on carers, both for support and for decision-making' (p.214, para.20.39).
- Transition planning for leaving in-patient care, at least 6 months before the young person is due to leave, should 'ensure the full involvement of the child or young person and (subject

to issues of confidentiality) those who will be involved in their care, including those with parental responsibility' (p.195, para.19.119).

- Providers are reminded of their duties to promote human rights, such as Article 8, by reviewing their policies covering '...visits from family and friends; and how to maintain family life (e.g. through contact with family members, such as sharing meals and celebrations, and performing roles such as being parents or grandchildren)' (p.216, para.20.43).

2. Consent

The law around consent is complex, with different requirements depending on age and mental capacity. While a child or young person may consent to hospital admission and/or treatment, 'it is good practice to involve the child or young person's parents and/or others involved in their care in the decision-making process, if the child or young person consents to information about their care and treatment being shared' (p.173, para.19.21).

Children under 16 years can consent to admission or treatment if assessed to be 'Gillick competent'³⁴, i.e. if they have sufficient understanding and intelligence to understand what is involved. Under the Mental Capacity Act 2005, young people aged 16 or over are assumed to have capacity to make their own decisions unless it is established that they lack capacity,³⁵ based on an assessment. Where this is the case, carers should be consulted about the 'best interests' of their young person.

Either way, the Code is clear that, subject to a child or young person's right to confidentiality, parents should be consulted about decisions concerning their child. However, parental consent is not essential if the child or young person is competent to

34. Name from case law. See Code of Practice (p.176, para.19.34) for further details.

35. Section 3 of the Mental Capacity Act states that a person is unable to make a decision if they are unable to: (1) understand the information relevant to the decision; (2) retain that information; (3) use or weigh that information as part of the decision-making process, or communicate their decision (by any means including non-verbal)

make their own decisions; and parents' role in decision-making is generally expected to diminish as a child matures and grows in independence (p.177, para.19.38-39).

3. Decision-making for young adults and 'Deputyship'

Family members can continue to make many decisions for their adult child, where this is in their 'best interests', as defined by the Mental Capacity Act 2005 (see above). This Act requires professionals to consult with family members when an adult lacks the mental capacity to make a decision and family members can challenge professionals if they feel that they are not being involved. Families can apply to the Court of Protection for 'Deputyship' (providing a clearer legal basis for involvement in certain decisions) if they feel that their involvement is being limited or decisions taken that are not in their young person's best interests. Several of the parents involved in this research had done this.

4. Nearest relatives

'Nearest relatives' have certain special rights, which are intended to act as a safeguard when someone is admitted for treatment. For children and young people, parents are usually the nearest relative, but not if a young person has married or has a civil partner (cohabiting for 6 months or more).³⁶ Nearest relatives have the right to:

- Apply for someone to be 'sectioned' (detained in hospital) and object to the same
- Discharge someone (with certain limitations)
- Ask for an independent advocate for the patient

Be consulted and informed about treatment.

5. Visiting children and young people in mental health in-patient settings

Where hospital admission is necessary, the Code of Practice states that 'the child or young person should be placed as near to their home as reasonably practicable, recognising that placement further away from home increases the separation between the child or young person and their family, carers, friends, community and school' (p.169, para.19.5).

The hospital (or other treatment) environment should be age-appropriate for patients under the age of 18 and include 'facilities for visits from parents, guardians, siblings, or carers' (p.192, para.19.103).

6. Local Authorities' duties towards children living in mental health settings for 3 months or more

Financial support may be provided by the Local Authority to enable family visits. Local Authorities have a duty under the Children Act 1989³⁷ to promote contact between children and young people and their families, when children are looked after by the Local Authority or accommodated in hospital for 3 months or more, in another area.³⁸

Local Authorities should also arrange for 'independent visitors' to visit, advise and befriend children and young people looked after by the Authority wherever they are, if they are not been regularly visited by their parents.³⁹

36. The Mental Capacity Act specifies in order of priority the nearest relative, as follows: (1) Husband, wife or civil partner; (2) Son or daughter; (3) Father or mother; (4) Brother or sister; (5) Grandparent; (6) Grandchild; (7) Uncle or aunt; (8) Nephew or niece

37. Schedule 2(8A) and (16) of The Children Act 1989

38. Described in more detail under LA duties towards accommodated children and the Visiting Regulations 2011.

39. Schedule 2(17) of The Children Act 1989

THE LEGAL FRAMEWORK: LINKS TO USEFUL RESOURCES

Human Rights – Right of a child to know and be cared for by parents; right to family life

The United Nations Convention on the Rights of the Child (full version): <http://bit.ly/1kFjlcX>

The United Nations Convention on the Rights of the Child (summary): <http://bit.ly/1elyzAx>

The United Nations Convention on the Rights of People with Disabilities (full version): <http://bit.ly/1ebQdup>

Guide from the Equality and Human Rights Commission (helpful): <http://bit.ly/25WSYgk>

European Convention on Human Rights (full version): <http://bit.ly/1foTqOD>

Children’s Services – Duties towards disabled children as ‘children in need’, ‘looked after children’ and children ‘accommodated’ for 3 months or more

Broach S., Clements L. & Read J. (2016) Disabled Children: A Legal Handbook (2nd edition), Council for Disabled Children. <http://bit.ly/1TbMQhe>. See Chapter 3: Children’s Services. Other chapters provide a detailed overview of all aspects of the legal framework, including case law. Authoritative and free.

Department for Education (2015) The Children Act 1989 guidance and regulations Volume 2: care planning, placement and case review (statutory guidance): <http://bit.ly/1M1Y3r7>

Health bodies duties towards children who are looked after

NICE (2013) Looked-after children and young people (standard 4): <http://bit.ly/1rl8PWA>

Special educational needs and disabilities

Department for Education and Department of Health (2014) Special educational needs and disability code of practice: 0 to 25 years. <http://bit.ly/1kOCi5i>

Residential special schools and children’s homes duties

Department for Education (2015) Residential special schools: National minimum standards. <http://bit.ly/1Po9vjY>

Department for Education (2015) Guide to the Children’s Homes Regulations including the quality standards. <http://bit.ly/1Po9vjY>

Mental health – Transforming Care

ADASS, LGA and NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. <http://bit.ly/21hBCrk>

Information on Care and Treatment Reviews: <http://bit.ly/1ZKgV6U>

Mental health rights and duties

Department of Health (1983) Code of practice: Mental Health Act 1983 (statutory guidance): <http://bit.ly/1IQ7HOT>

Department of Health (2014) Getting it right for people with learning disabilities. Going into hospital because of mental health difficulties or challenging behaviours: What families need to know (recommended, very useful): <http://bit.ly/1VUtVb4>

Information on the Mental Capacity Act 2005: <http://bit.ly/1PWwV5A>

MIND briefing with information about the role of the ‘Nearest Relative’: <http://bit.ly/1rlbgs4>

A range of useful resources on mental health are available freely from Challenging Behaviour Foundation website (<http://bit.ly/1VUtJbH>). Including:

- Meeting the Challenge Guide 4: My family member has been sent to an inpatient unit – what do I need to know?
- Meeting the Challenge Guide 6: How do we plan for a successful discharge for my family member?
- Meeting the Challenge Legal FAQ (frequently asked questions): Explaining the rights of the person being treated and the rights of family members.

Mental Capacity Act template letters: If you're concerned that you are not being involved in decisions affecting your family member and want to challenge this.

Also on the Challenging Behaviour Foundation website (<http://bit.ly/1U3H2BY>) you will find further briefings including: Meeting the Challenge Guide 7: How do my family member's rights change as they become an adult?



Photo credit: © Simon Ansley

CALL TO ACTION!

PROMOTING GOOD PRACTICE

The main aim of this research was to promote good practice in helping children and families to keep in touch, when a residential placement has been made. The report includes practical resources to help local settings and service commissioners to review their policies and practice:

- a 'what works?' checklist for settings
- a 'what works?' checklist for Local Authorities and health commissioners
- families' vision of good keeping in touch arrangements (colour graphic)
- Stop and Think! 5 key questions for residential settings and commissioners (colour graphic).

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

- use the checklists 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.⁴⁰ **We urge Transforming Care Partnerships 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)
- 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.

40. 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.



Photo credit: © Simon Ansley

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

General enquiries

Email: info@thecbf.org.uk

Telephone: 01634 838739

information and support

Email: 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



**The Challenging
Behaviour Foundation**

