

## Scenario 1 – Diagnosis and early years

Emily and Prem rushed to the hospital - Emily was in labour with their first child. After a long labour Emily gave birth to Oliver and both parents were delighted. Delight quickly turned to fear as Emily realised something was wrong. Oliver was very floppy and didn't appear able to feed.

Emily and Prem were eventually told that Oliver was suffering from a rare genetic syndrome. The consultant in the hospital who broke the news to them had a direct and abrupt manner. He explained that the syndrome was due to an "imprinting defect", which only occurs in 5% of cases and meant that more genetic testing was required. Emily and Prem were not interested in the statistics – they wanted to know what it meant for Oliver and for their future as a family. When could they take him home? The consultant told them "not to expect too much", that Oliver would be unable to talk or live independently, may have problems with his vision, would struggle developmentally and may have emotional and behavioural problems. Emily and Prem were overwhelmed.

When they got home, apart from regular hospital appointments for testing and with specialists only able to discuss specific issues, Emily and Prem felt very much alone and often took their stress out on one another. They were reluctant to meet up with those they met at antenatal classes and their family did not know how to respond to Oliver's diagnosis. Apart from a one side of A4 printed sheet, listing all the problems Oliver would be likely to encounter and some website addresses, no one gave Emily and Oliver any information.

Emily and Oliver began to research the syndrome themselves and found out as much as they could, becoming experts in a matter of months. By the time Oliver was two, they were coping well, managing family meals in a way which helped control his need to eat and keeping to a routine which helped him feel safe and happy. They had started to recover from those early months.

However, at this stage, Oliver's behaviours began to change. Oliver had started to demonstrate an obsession with shoes – collecting up all those he could find. Oliver's behaviour was becoming increasingly difficult to manage often resulting in broken property or injury to himself and Oliver had also started to pick at any graze or scab on his skin and the area surrounding it, leading to nasty sores. When Emily tried to seek advice she was told by the Health Visitor and GP that this was just the "terrible twos" and Oliver would no doubt grow out of it. Emily and Prem were not convinced by this but yet again found themselves in unknown territory, with no one to advise them on what to do to support their son.

## Alternative Scenario 1 – Diagnosis and early years

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Emily and Prem were eventually told that Oliver was suffering from a rare genetic syndrome. The Consultant who explained this to them had a clear but gentle manner. He had been on “breaking news” training and was aware of the feelings Emily and Prem were likely to experiencing, as well as the need to explain Oliver’s condition to them. He explained that the syndrome was due to an “imprinting defect”, which only occurs in 5% of cases and meant that more genetic testing was required. He also explained that they were likely to have lots of questions but that he didn’t want to overwhelm them with information before they were ready, that they would be able to take Oliver home soon but would just have to wait a little longer while initial tests were carried out. He introduced them to a specialist nurse who was also able to talk them through the implications and answer their questions while Oliver remained in hospital.

When they got home, Emily and Prem met professionals who were able to support them close to home. An Early Support Worker came to visit them and explained that she would be working in partnership with the Health Visitor and the local Child Development Centre to support the family and to support Oliver’s development. Those available to support Oliver included a Speech and Language therapist, Occupational Therapist, Clinical Psychologist and Physiotherapist. All of these professionals were involved in supporting Oliver as he grew older and information about his development was shared across the team so the family did not have to repeat the same information to each.

The Early Support Worker also helped when the family felt they were constantly at the hospital for tests and consultations, implying something was “wrong” when actually at that point Oliver was starting to respond and to smile and Emily and Prem just wanted to enjoy family life with their son. The Early Support worker introduced them to Contact a Family and other voluntary organisations who could put them in touch with families in similar situations. The Early Support worker also put them in touch with the local children’s centre which was very inclusive. They were nervous about taking Oliver there at first so the centre paired them up with another family who took them along and introduced them to other local families. This gave Emily and Prem the confidence to take Oliver to a local playgroup and also to get back in touch with their antenatal group. Through these groups they started to form strong friendships with other local parents.

By the time Oliver was two, the hospital visits had reduced and the family had less frequent contact with their Early Support worker as they were coping well, keeping to a routine which helped Oliver feel safe and happy and supported by a network of friends.

However, at this stage, Oliver’s behaviours began to change. Oliver had started to demonstrate an obsession with shoes – collecting up all those he could find. Oliver’s behaviour was becoming increasingly difficult to manage often resulting in broken property or injury to himself and Oliver had also started to pick at any graze or scab on his skin and the area surrounding it, leading to nasty sores. This was making it difficult to take Oliver out and about.

Oliver’s GP was concerned about his injuries and sores but was conscious that she did not know enough about Oliver’s condition and about challenging behaviour. She knew there was a local Challenging Behaviour team and contacted them to get hold of the pathway they had developed to help guide practitioners.

Emily and Prem contacted their Early Support worker to raise their concerns. The Early Support worker also contacted the local challenging behaviour team. An appointment was set up with a behaviour specialist at the local Child Development Centre. The behaviour specialist undertook a functional behavioural analysis and worked with Emily, Prem, their Early Support worker and Health Visitor to develop a Positive Behavioural Support Plan for Oliver.

Emily and Prem were given information about the causes of challenging behaviour and were put in touch with the CBF so they could find out more. The plan was presented in an accessible way, so it could be shared with playgroup staff and others, to help them support the family. Oliver's behaviour was kept under review and his family were offered training in PBS to support them in managing his behaviour.

Emily and Prem were re-assured that the local support which had been available initially on bringing Oliver home was still available when they encountered difficulties and that they knew they could access the right support via their Early Support Worker. The PBS plan helped them to build up confidence to take Oliver out and about again to playgroup and to have friends round to visit.

## **Scenario 2 – Behaviour escalates**

Bo was 10 years old when his parents had to move from London to the South West. Bo has severe learning disabilities and behaviours described as challenging. He lives at home with his parents and his older sister. Bo enjoys music, playing on the i-pad and swimming. Bo's family and staff at his school were aware of the triggers for Bo's behaviour and kept his communication diary up to date.

Bo's parents were aware that the move might be difficult for him and worked very hard to find a place to live near an appropriate school. They worked hard to communicate the changes to Bo and to make sure that when they arrived he was able to take part in his favourite activities, to help the transition process. Initially, Bo seemed to settle in OK to his new school. However, after a couple of months his Mum could tell something was not right. His challenging behaviours were starting to increase in both frequency and intensity and he had developed a new behaviour of bashing his head against the wall. Bo's mum asked for a meeting to discuss this with the school – but staff at school said Bo seemed fine and she had the impression they thought she was exaggerating her worries.

Two weeks later her worries were confirmed when she had a phonecall from the school saying that Bo had thrown a chair at a teacher and was being suspended. She drove to the school to pick him up, incensed that a school which was supposed to be expert at supporting children like Bo had been unable to detect that something was wrong – despite her warnings.

After months with Bo at home, with his behaviours escalating and no prospect of a resolution with school, his family were reaching the end of the ability to cope and concerned about their daughter too. Bo had hit his mum a number of times and she feared that he may do the

same to his sister. Bo was up every night, often destroying his room and no-one could sleep. Children's Services recommended a residential special school. Bo's mum felt bereft at the thought of Bo leaving home – he was only ten years old and the school suggested was over 100 miles away. But she couldn't see how the family could continue as they were. Reluctantly, Bo's mum and dad agreed.

Bo's parents were told not to visit him for the first six weeks while he settled in. It was the longest six weeks of their life. When they finally went to visit, they found that Positive Behavioural Support was being used to support Bo. They had never heard of this approach before and could see it was having a remarkable effect on his behaviours after only six weeks. They also found that he had been seen by a Dr who diagnosed an ear infection, which was likely to have been causing him much pain.

### **Alternative Scenario 2 – Behaviour escalates**

Bo was 10 years old when his parents had to move from London to the South West. Bo has severe learning disabilities and behaviours described as challenging. He lives at home with his parents and his older sister. Bo enjoys music, playing on the i-pad and swimming. Bo's family and staff at his school were aware of the triggers for Bo's behaviour and kept his communication diary up to date.

Bo's family worked with his school and Social Worker to develop a transition plan for the move and they shared this with his new Social Worker and school in advance of the move. It included his behaviour support plan, communication passport and Person Centred Information profile.

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At the meeting school staff listened to Bo's mum's concerns and brought along their recent observations to see if between them they could identify any setting events, triggers or possible causes such as anxiety about the new environment and people. The school used a PBS approach to manage behaviour and were confident they could find a way to address the recent escalation in behaviours once the causes were identified. Following discussion, they were unsure what of the cause was so agreed to call in a Speech and Language Therapist and a Behavioural Psychologist who worked together alongside the school to take forward a proper assessment. In the meantime, both school staff and Bo's parents kept records on ABC charts so the Psychologist had as much data as possible. They also asked whether Bo's mum had taken him to the GP for a check up recently.

Bo's mum made an appointment with the GP in the new area, pointing out that he would need the first appointment of the day as part of the reasonable adjustments required to enable him to access health care. Bo's notes had not yet arrived from the previous GP and been put on the system, but the surgery agreed to call the previous surgery and asked to see Bo's communication passport so the GP was prepared and able to communicate effectively with Bo and his Mum. The GP did standard checks and found that Bo had an ear infection, for which he was prescribed antibiotics. Following the course of antibiotics, Bo's head bashing decreased.

Bo's parents regularly attended meetings, workshops and training at Bo's school, which worked in partnership with parents and held joint training events for teachers and parents. This helped them to meet other parents and settle into the new community. They met one family whose son had been suspended from school after throwing a chair at a teacher. They found there had been a clear plan developed for getting this boy back into school and that the local intensive support team had worked with the family and the school to help support that process. He was now back at school and his parents were grateful for the crisis support which had got them through that difficult period.

Bo's family felt that the information and training they had all gained from school on behaviour and communication had really improved their quality of life and reduced the frequency and intensity of challenging behaviour. They were also grateful that the school had referred them on for further support, including sleep management, which had made a significant difference.

### **Scenario 3 – Leaving school**

Nina loved school and attended a special school 30 minutes' drive from her home with staff who were skilled in supporting her. She enjoyed a range of activities at school and at home and particularly liked visiting the park and the beach with the family dogs and going into shops where she knew the staff. Nina has learning disabilities, epilepsy and exhibits behaviours described as challenging including repetitive hand flapping to the exclusion of other activities, verbal aggression and non-compliant behaviours. Nina brings much joy into her family's life. They also find supporting Nina incredibly difficult – especially when they are out and about and Nina shouts or screams or sits down and refuses to move. Often this leads to criticism from members of the public.

When Nina was in year nine, her parents were called in for a review meeting at school. The school SENCO led the meeting and had notes from Nina's Social Worker. Nina's parents had not fully realised that this review meeting was apparently the place where they were to consider Nina's future beyond school. The school had sent information, but it had coincided with a bad week. Although they were pleased that thought was being given to Nina's future, they were not really clear what all the options were. During the course of the meeting it became clear that the options for Nina on leaving school seemed to be remaining in the family home or going to a residential college miles away from home. Then there would be the issue of what next after residential college?

In the following years, Nina's parents began to look into the options further and discussed the issue with parents who had older children. Nina's parents both worked, so they would be unable to support her at home without help. They found to their dismay that if Nina were to remain at home past the age of 18, much of the support they had had to date from children's

services would disappear. They felt increasing fear about the future and began to look at residential colleges. They were told that they should consider somewhere with an adult unit attached, so Nina could move on there at the age of 18.

Nina's parents liked what some of the colleges had to offer in terms of education and support but they wanted her to live at home while she attended college. They also wanted to find her somewhere to live near home when she was in her twenties – so they could continue to support her and be part of her life, with help from others. They were sure this was what Nina wanted too. She loved her siblings and all her local haunts. This option did not seem to be on offer. They realised there was a huge task ahead in terms of researching housing options, direct payments, personal budgets, employing staff...it was overwhelming. Nina's parents were also worried about losing the great clinicians from the multi-disciplinary paediatric health team who had known Nina for years. They tried to discuss their worries with adult services but were told Nina was still the responsibility of children's services so they were not able to offer any support beyond signposting until she turned 18.

### **Alternative Scenario 3 – Leaving school**

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Nina had a key worker who referred her to the local behaviour support team. The team had worked with Nina's family and school to develop a positive behavioural support plan for Nina, which helped to improve the quality of her life and reduce behaviours that challenge.

Nina's key worker set up a pre meeting before her year nine review to ensure that her parents understood what the review would consist of, who would be there and to explore what outcomes the family might want from the meeting. She suggested they think about their ideal scenario for Nina after leaving school and what support they would need to make that a reality. Nina's parents and keyworker all spent time with her to discuss her views. Nina was better able to communicate about the here and now than the future so her family and key worker thought about how best to ensure her views and wishes were central to the year 9 review. They decided to talk to Nina, using her PECs, about the things she likes best – as those would be the elements they would want to ensure formed part of her support on leaving school. Nina was clear that she loved the company of her sibling, her dogs and her local haunts including the beach and shops where she knows the staff.

Nina's keyworker told her parents about the local transition team, who would be present at the review and the local transition pathway. This team would help to bridge the gap between children's and adults services. She also thought they might want to consider a personal budget, which they had not used before but which might help them to create the right package of support for Nina.

Nina's parents arrived at the review knowing who was going to be Chairing the meeting, who would be present and what documents would be taken into account. The review started with a summary of Nina's views and wishes and then went on to consider the ideal outcome Nina's parents were hoping to achieve. This involved living at home and attending a local college in the short term, then looking for suitable housing and employment near to home as Nina grew older.

The co-ordinator from the transition team agreed to take the lead in working with Nina's parents to put the right support into place to achieve transition, while Nina's parents agreed to visit the two nearby colleges.

When Nina was nearer to the point of transition to adult services her multi-disciplinary paediatric health team led a transition clinic focussed specifically on her health needs, this involved the paediatric clinicians helping to manage her epilepsy and speech and language needs and those who would do so from the adult health teams. The co-ordinator from the transition team was at this meeting and able to work alongside Nina's parents to ensure that her health needs were understood within the wider context of her wishes and plans for the future. They agreed a health plan summary covering all issues (including communication, behaviour and reasonable adjustments required), so there was a clear report to support any onward health referrals in plenty of time.

Nina's parents were daunted by the significant changes and challenges ahead but reassured that the transition team and Nina's keyworker would help them to negotiate the path ahead.