
Families' stories

[Source: National Deaf Children's Society](#)

The stories that follow are from families of deaf children and young deaf people in the UK. The stories explain the people's experience of making the decision about whether or not to have a cochlear implant. Each story is told in the child's or family's own words. As a parent, you will know that every child is different, and that all parents feel strong emotions when making decisions that affect their child. These stories reflect this, so you may want to take your time in reading this section.

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Freddie's story

Freddie lost his hearing through pneumococcal meningitis at 10 months – we feel lucky. Since then, life has been one huge rollercoaster of emotions. From the low of being prepared for the worst as Freddie lay unconscious in intensive care to the highs of him ordering “mummy, Freddie wants milk downstairs now please”. Like all good rollercoasters, there have been many twists and turns along the way.

When we were officially told that Freddie was profoundly deaf it came as no great shock – John and I had already observed him sit through repeated hearing tests blissfully unaware of the ear splitting noise booming from the loud speakers. It was a humbling experience. By the time cochlear implants were first discussed we had already began researching the technology.

The initial cochlear implant assessment appointment proved another white knuckle ride – a day filled with anticipation and anxiety. The morning involved a procession of meetings then the hard part – a two hour wait for a decision. Armed with Freddie's MRI scans, our doctor informed us that the meningitis had caused severe ossification in both ears and that unless the surgery was performed quickly they may not be able to physically fit the implant and Freddie would never be able to access sound. Whilst we were taking all this in, our doctor advised that the surgeon had slotted in the operation for four weeks time!

Freddie had his operation on 5 November. It seemed that time stood still for 5 hours as the surgeon, using a specially designed implant, inserted 17 out of the possible 21 electrodes – a considerable achievement given the extent of ossification. Even the surgeon was thrilled.

After we learnt that only 70+ people in the world have been fitted with this particular device.

Switch on happened at 18 months – a little longer than usual due to a post op infection and the Christmas holiday season. But the wait was well worth it. To see Freddie smile and his eyes light up was a very emotional moment. However, it took some time for the family to realise that switch on was the start of a long but rewarding journey.

Freddie is now a lively and loveable 4 year old. Like all boys he is into everything and loves dinosaurs. He loves listening to stories and his concentration levels and interaction with other children have improved dramatically in the last year. There is also less stress and frustration for all of us as Freddie makes himself increasingly understood. We are careful to promote language in a natural way which is meaningful and fun. Even simple tasks such as making milkshake are used as colourful word games. The joy is that we never tire of hearing Freddie talk or say new words.

In our desire to extend his verbal communications skills we often forget what Freddie has achieved already and we are always grateful to people who comment on how well he has developed since they last saw him. We find this incredibly motivating.

Freddie has good signing skills and his lip reading abilities never cease to amaze us when he takes off his implant at night. For a while he wouldn't let us take it off at night, but we were advised to encourage him to remove it as it can lead to pressure sores at the implant site.

His 6 year old sister, Holly, is very patient and loving towards him – even when he annoys her - and acts as his interpreter when required. We are conscious to keep Holly informed and involved with all that goes on and give her time too.

Our biggest fear at this time is Freddie's lack of co-ordination, which is a problem as he prefers running to walking and has a tendency to bump into obstacles. It is as if he concentrates on where he needs to get to rather than how to get there. He is currently receiving physiotherapy to help with this as he cannot afford to damage his implant.

Freddie has now received his SEN statement confirming his placement at the local hearing impaired unit – which he loves. We are delighted as Freddie is clearly in the right place and receiving the right support for his needs. We feel lucky that the school is on our doorstep.

We have had tremendous help along the way and we are eternally grateful for the support of the local speech and language therapist and educational services particularly in the early days. We don't know what the future holds for Freddie but we remain positive and one thing is for sure it will be one hell of a ride.

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Matthew's story

Matthew was 6 months old when he was diagnosed as being profoundly deaf. Our paediatrician referred him almost straight away to the cochlear implant program where we

were put on the waiting list.

In the meantime we were to find out that Matthew also suffered from a brain condition called pachygyria that affects both his physical and mental development. As a result of various complications, Matthew was three by the time all the necessary checks had been completed to show that physically he was suitable for an implant.

At that time, the implant team had very minimal experience implanting children with learning difficulties and couldn't say that Matthew would gain any more than environmental awareness from an implant. By this time we had been signing with Matthew at home for over 2 years, but he had barely picked up more than a dozen signs and our communication was very limited. We were having to work very hard with him to develop his sign language, and felt that if he was implanted, we would have to change our focus to develop his hearing. We were concerned that if we couldn't develop communication through his implant, and if we didn't continue to focus heavily on signing, then we might end up with no real communication with Matthew.

It was a difficult decision, but we felt in the end that it would be better not to go ahead with an implant. This meant that we could continue to focus on signing with Matthew without introducing what we felt would have been yet another complicating factor for Matthew. It did take quite some considerable time for Matthew to learn enough signing to communicate at his own level, but he has continued to progress well and can now hold quite a conversation and is never lost for 'words'. We have no regrets about the decision we made, which was right for our son at that time.

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A child with sequential bilateral implants and a big gap between them!

Bradley was born profoundly deaf into a hearing family with no history of deafness. He had four older hearing siblings. He received his first implant at age 3 and a half and immediately heard sounds for the first time. In the summer following implantation, the whole family attended the John Tracey summer school in California, where we discovered that his deafness was most probably due to Waardenberg syndrome, but more importantly, learnt how to encourage Bradley to listen with his cochlear implant and to get tips on how to develop his spoken language. We came back with high expectations of what Bradley could achieve.

We decided to send him into our local village infant school with support, believing that he would learn language by listening to and copying his hearing peers. This did seem to be the case. He copied in a mainstream school admirably, overcoming the various acoustic and social issues that did sometimes arise.

However, by the time the transition came for secondary school, the language of the curriculum was so much harder. Bradley got very tired listening to copious amounts of new and complex information in all the various subjects. He needed to listen hard to the answers of his peers and to formulate his own ideas and opinions. The concentration was more difficult. He would turn his head around so that his friends could speak into his implanted ear.

We began to explore the idea of a bilateral implant. It was obvious that the UK was behind many other countries with this concept. The implant team was supportive, recognising that Bradley was a very good unilateral user. However, this was pioneering stuff. There was no known cases of the results of a bilateral after such a long interval. These were not ideal conditions. Eventually Bradley had his bilateral when he was nearly 11, eight years after his first. The results were amazing. Within 6 months, he could hear nearly as well in his newly implanted ear. His listening in the classroom was easier. He could have friends sitting on either side of him. He could hear more easily in noisy situations, and got less tired listening in day to day life. Most importantly, he hears with both ears, and that just has to be better.

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William's story

What follows may prove uncomfortable reading. I have not written it seeking sympathy, neither have I written it to worry parents considering an implant, nor to criticise any of the medical and professional teams that have been so supportive over the last five years. I have no "deafness" agenda. All I ask is that with children like William, where deafness is just one of a complex web of issues, we do not lose sight of what best serves the child as a whole.

When a child is born every family sets out on a journey. When that child is disabled the road they travel is far from smooth. We started our journey with our first son, William, in March 1999. Within a few days it was clear that things were not exactly as they should be. We were fortunate to have an understanding and trusting team of GPs and health visitors who never once questioned our concerns or observations and over the following months helped us through the rounds of tests and referrals.

William was diagnosed as profoundly deaf, but there was more. He was slow to achieve the landmarks that most babies do, slow to lift his head, slow to sit and walk. Without boring you with the history of scans, tests and consultations, by the age of 18 months William was diagnosed with CHARGE syndrome.

In many ways it was good to have a name to put to William's problems and we at last knew where the boundaries lay. Whilst the diagnosis identified a number of problems, we became absorbed by his hearing loss. We started to sign with him from early on and began investigating the possibility of an implant. After the usual assessment process and some pauses for other minor operations, the team at the hospital undertook the surgery in April 2002. We were no strangers to hospitals and surgery - in his three short years William had been anaesthetised at least seven times.

After switch-on William made slow progress, everyone taking hope from his happiness to wear his headset all day from the very beginning. Six months on and after a change in mapping strategy he made a step forward and started to turn to claps – a revelation to us. He no longer needed to be within waving, touching or stamping distance in order to get his attention.

In April 2003, just as we started to see a brighter future for William, it all stopped. What started as a slightly prominent implant site became a patch of red skin, and a cause for concern to the

surgeon. This in turn became emergency surgery to reposition the package and ended in the discovery of a large infection necessitating the removal of the implant. The hospital had no hesitation in offering re-implantation on the other side.

Sitting with William in the recovery room at the hospital the questions started spinning around my head. As the next few days and weeks passed more questions kept coming. Could we put William through this again? What if a second implant failed or the infection recurred? What if he made better use of a second implant and then it failed and we had to take away this gift of sound? If we did re-implant what kind of life would we let him lead, worried that the slightest knock could cause damage? These are all the kinds of questions asked the first time around, but this time we knew that he had made slow and limited progress with the first implant and the question “How much benefit would William really get from an implant?” became central.

Thank goodness for my husband, a kind and loving man who nonetheless has the ability and strength not to let raw emotion cloud his judgment. He said, “Don’t try and make a decision, identify the questions we need answering, answer them and then the decision will have made itself.” He was right.

With the help of the hospital team we spent time looking more closely at CHARGE syndrome and the success of implants for children like William. Very little data exists, however, what soon became clear was that the children we had heard of remained reliant on signing; implants gave them environmental cues, which are of course helpful but they remained signers. Whilst the hospital put the infection down to nothing more than bad luck, we never stopped wondering whether there was something about William that made him more susceptible to it and we were not about to try again with an implant just to disprove that hunch.

The more we thought about it the more we realised that William was not just a deaf child. His CHARGE syndrome, the way his brain and body worked was at the heart of this issue. We needed to look at William as a whole, not just his deafness. We had been so focused on helping to give him some hearing that we had tended to ignore other issues like his general but significant developmental delays. We had come to understand that these had a greater impact on his ability to adapt to and process what the implant was giving him than we had previously realised.

By this time we were anticipating William’s move from preschool to school and were determined that it should be as smooth as possible for him. Without an implant we had a stable, immovable baseline for everyone involved in his care to start with.

Whilst we will never regret our initial decision to have an implant, with hindsight we realise it had been a huge distraction for everyone around him. Although we had continued signing with him, we had been pinning too much hope on the chance of him becoming oral. Without even realising it, we had stopped pushing ourselves to expand our own and his signing vocabulary – we were treading water. Family and friends at times seemed to forget he was deaf; it was as if by seeing him with the implant they thought it was just a matter of time before he would be

talking like any hearing child.

The discovery of the infection really made us stop and reassess William's situation in a way I think we might never otherwise have done and by doing so we reached a greater understanding of our child and his situation. In the past we used to say William was a deaf child who just happened to have CHARGE syndrome. Now we say William has CHARGE syndrome, which includes being profoundly deaf.

I will never forget my journey home from London after telling the hospital team that we would not be opting for another implant. I sat waiting for a feeling of sadness and panic to overwhelm me; instead I was enveloped by a wave of relief and determination to do all I could for William as he is now.

It may appear to some that we gave up too soon on the implant. We should have tried again for William's sake. In truth, we were given the opportunity to stop and look closely at William as a four and a half year old. We were able to look back and realise how much more we understood about him, his abilities and our expectations than we had two years before.

More than a year on from the removal surgery and William has settled well into a mainstream school with a unit. He has signed support all the time and is making slow but steady progress. At home we are all happily signing, including his two year old brother, and continue to feel that we have made the right decision for William. The path may have changed direction, but our journey with William continues.

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Natalie's story

When our daughter Natalie was born in 1993 she was very ill. After many tests it was found that she was suffering from congenital Cytomegalovirus (CMV); this can have many side effects of which Deafness is one. At four months old she was diagnosed as being profoundly Deaf and was referred to hospital for assessment and hearing aids.

Ironically, prior to having Natalie I had worked in Deaf and other special schools and had a good knowledge of British Sign Language (BSL), so as soon as we knew that she was Deaf I started using BSL with her. Other members of the family – her dad, grandparents, aunts and cousins all went to college to learn it too.

Because of her other medical conditions, she couldn't lie on her tummy and do the "usual" baby things, so we spent a lot of time looking at books and other things about the house, just showing and describing things to her. She seemed to soak up language and used her first sign (bird) at about 10 months. From then on she never stopped and her signing skills have always been above age appropriate.

The subject of cochlear implantation arose when she was about 18 months old. It was still very new back then and the expectations were not high - "she may get an awareness of some environmental sounds". It was a very tough decision to make particularly as it appeared that

some CMV children were not doing well with implants.

Communication was not a problem with us, but there is a big hearing world out there and one day she would have to go out into it! Even if she only heard environmental sounds, we hoped it would help keep her safe e.g. if she could “hear” a lorry or us shouting “stop”. Even the strongest hearing aids were of no use to her; we wanted to give her every opportunity in life, if we left it until she was old enough to decide for herself, it would be too late; We thought long and hard and finally decided to give the go-ahead, we would give her this opportunity and if it didn’t work or if she didn’t like it, then when she was older it would be her choice not to use it.

She received a body worn implant just before her 3rd birthday and was “switched on” in September 1996. This went brilliantly until they tried to turn the “volume up”; she didn’t like it and got very upset, so for the next few weeks it was left on a very quiet volume. Also, for the first few weeks she hated it when it was first turned on. We had to make sure there was absolute silence, switch it on, on a low setting, and then gradually increase it as she got used to the sounds going in. Once she had it on, she was fine and it didn’t bother her at all.

This lasted about four weeks after which we have never really had a problem. She has four electrodes turned off, as she doesn’t like the feeling/sound that they produce, but this has never been a problem. After the initial few weeks she has never looked back! She started responding to sound within weeks and was answering to her name by Christmas. She had never really used her voice before, but it was only a matter of months before she was saying “mmmm” for mummy and “u” “u” for woof, woof!

When she was nine she received a behind the ear processor which helped to increase her “hearing” range. She has continued over the last eight years to make steady progress and now considers herself to be bilingual. She is age appropriate and fluent in both BSL and spoken English. Until last year she went to a fully integrated mainstream unit and did well, but as she grew older it became apparent that her needs were changing and so we moved her to an Independent Bi-lingual Deaf School.

The implant has far exceeded all of our expectations – she can even use a phone with familiar adults. She has just passed her year 6 SAT’s English exam and gained level four and next year will be starting to learn her third language - French. Natalie is very proud and happy to be Deaf, but she is equally as happy and proud to have her implant. As she herself says: “It has given me the best of both worlds!”

The implant is not a miracle cure for Deafness, she is Deaf and will always be Deaf; we felt then (and still do) that it was simply the best available hearing aid. If when she is older she chooses not to use it, it will be her own decision and we will agree with her, knowing that at least we have given her the opportunity to make that choice.

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A family’s story

In 1990 our first son was born. Thirteen months later he was diagnosed profoundly deaf. He

was fitted with hearing aids but we had no communication with him, which was very frustrating for him and ourselves, therefore we went to sign language classes. Three years later we had our second child, a daughter, who at six weeks old was too found to be profoundly deaf. She too was fitted with hearing aids.

Although our son did get a little benefit from his aids our daughter didn't. However, they both seemed happy and we were just relieved to have some communication with them through sign language. However in the back of our minds we always wondered if we were doing the best for them. They both attended special schools and nurseries with a unit. At this particular time there was lots of publicity about the "Bionic Ear" – the cochlear implant.

We read about it and read about it and decided to find out more and so went to an information day run by a paediatric cochlear implant centre. We listened to lots of stories, all different cases. At this time our children were 6 and 3 years old. We gave it a tremendous amount of thought and decided to look at the possibility of offering our children what we decided was just the best hearing device on the market.

We didn't want to change them into hearing, after all we were proud of them but just wondered if in the long term it would make their life easier as they got older. After lots of tests and assessments we decided to go ahead with it, it wasn't easy especially when we had to think of the risks involved, although small, we had double the chance.

As our son was classed as being older than recommended at the age of eight, we felt he was old enough to talk it through a little. He was afraid, and so after lots of consideration we decided to let our daughter who was nearly five have it done. After all she didn't really get any benefit from hearing aids and so this had to be worth it. Also we felt that if our son saw his sister come through it all then he would feel happier about it. So that was what we did. It was a very difficult time. Their operations were just six months apart, thus giving us some time with each child individually post-op. The check-ups and tuning were quite exhausting for them and for us. However, looking back it was all well worth it, from our point of view and our children's.

Yes, they are still deaf and always will be, and are proud of being deaf. We still use sign language but don't rely on it as much as before their implants. They are able to join in things easier with the hearing world but still like to be part of the deaf world too. You could say they have the best of both really which is all we wanted. As they grow into adults it is their choice which route they take but at least we know we have offered them everything available.

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Holly's parents' story

Holly was born partly hearing. Her parents and grandmother (mother's side) are profoundly deaf, her brother Lee is hearing. When she was under 1 year old, we took her to the Audio department at a hospital in London to check if she is deaf because we noticed she did not response when the noise was loud comparing her to her brother who picked up the sound well.

After the Audio team tested her they told us that she was partly hearing and provided us one

hearing aid to change to each ear every hour but the hearing aid kept whistling, it affected her partly hearing ear and it deteriorated rapidly then she became profoundly deaf. They also provided another hearing aid for the other ear. We continued to contact the audiologist until they transferred her to a different hospital. They replaced her hearing aids to the powerful ones she used when she went pre-school and at home. She found that it didn't really help her and one day she surprisingly, asked us that she wanted to have a cochlear implant which stunned us and had to do some thinking about the idea. She wanted an implant because some children at her school had one and she noticed that they are listening and speaking well better than she is. We discussed the ideas with the audiologist before we decided and the doctor explained that it was at an early stage for Holly, and better to wait until she is a bit older. Holly constantly tells us the hearing aid isn't helping her. We again discussed with the doctor and we agreed to send her to a hospital for children in London.

The assessment took nine months for further tests and finally the implant team took their meeting and agreed that Holly is suitable to have one. Holly was very happy and looking forward to having it. The operation took place April 1996 she was six and a half years old. The operation was successful and took 5 hours.

One month later we returned to the hospital to receive a new speech processor and accessories for the implant. We had to go there for the next three days for the 'switch on'. She responded to all various sounds she is able to hear the sound different between high and low pitches. Which she never did with the previous hearing aid, she can hear bird pecking which was her first sound as she walked out of the hospital on the first day, microwave beeping, kettle boiling, etc. We were amazed when she tells us about the sound she could hear that she never did with hearing aid. My son Lee told us that he could hear Holly's voice much more clearly than before. We find a cochlear implant is a great benefit for Holly it is really worthwhile. Holly's languages at home are sign language for her grandmother and us but with her brother she speaks. She signs with most deaf people so they can understand but speaks with hearing people. She also lipreads but can hear without looking.

Now she is 15 years old and she is still attending mainstream high school, which is the local school. She uses behind the ear processor not body processor. She has had it for eight years now and is very happy with it. She did not regret having the implant. She is very helpful to us when we are out shopping, or hospital or whatever. She interprets for us because we find it hard to understand what they are saying sometimes but Holly had a good communication with the hearing people.

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Holly's story

I've had my implant since I was six and a half, and had it for eight years now. When I first had my implant switched on it took me a while to get used to it because it sounds totally different to my hearing aid. Hearing aid never really helped me because it was always whistling. I constantly took my hearing aid off, I couldn't understand what anyone was saying, with my implant it helped me a lot and I picked up lots of sounds.

My first sound was hearing bird pecking on the ground, as I walked out of the hospital after the first day of switch on, it was amazing. It was much better than what I expected of it. I don't regret having it and I never will, I don't think I'd be where I am now if I didn't get the implant. I know it sounds terrifying going through operation just to get an implant, but it is really worth it. I know for a fact that my listening skills had improved over the years since having it and my speech. I sometimes feel like I'm a hearing person when I can hear people talking without looking and forgetting that I got my implant on because I can't feel it, but I know deep down I never will be hearing. I am in both deaf and hearing world and I would like that to continue. I go to local mainstream school and I am coping very well there.

I have supporters in some of my lessons to take notes or anything like that although I don't think I need it because I understand my teachers well. I am in my last year at school and I am hoping that I will do well in my GCSEs next year. After that I will go onto college to study childcare because I want to work with deaf children in the future.

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Kasima's story

At an early stage of my daughter Kasima's life it became apparent that she had some difficulty with her hearing, by the age of two she was diagnosed as being profoundly deaf. Over the years learning to adapt to her circumstances was very difficult and put the family under a lot of pressure.

After many consultations and meetings Kasima at the age of nine years old was referred to hospital to undertake medical tests to ascertain if there was anything that could be done to increase her hearing levels.

In 1995 Kasima was operated on and was implanted with a cochlear implant. This was a very stressful but exciting time for Kasima and the family, possibly we were told, Kasima would be able to hear sounds of some sorts if the operation went successfully. One month after the operation the day of truth had arrived; we were due back at the hospital to switch the implant on. Everything seemed to be fine and they set the implant up to receive 18 channels. On returning home I noticed Kasima becoming really excited and enthusiastic, what happened next was amazing. Kasima with the car window wide open started to hear sounds; you could see she was unsure about placing the sounds to visual items. Kasima then began to constantly inquire to what made what sound and where that sound came from. She was so excited, when we reached home she was showing everybody the hearing device and then the doorbell rang and she moved towards the door and that was the emotional sight for me as I now realised what this device meant in relation to Kasima's life.

Just being able to do something as simple as answering the front door, something that we take for granted on a daily basis. As time went by Kasima gradually became familiar with everyday sounds like the TV, microwave, Hoover and doorbell, family member's voices and tones. Along with the joy of being able to hear sounds Kasima from an early stage took great responsibility for the up-keep and maintenance of her hearing device, cleaning it regularly and changing the batteries.

Returning to the hospital three months later the speech therapist and the audiologist were shocked and surprised at the progress Kasima had made so they decided to increase the channel input by two - up to twenty. After the review Kasima started to engage with the local speech therapist with the implant. During her speech therapist sessions she began to pronounce her nouns and vowels and started to develop single words that later began to developed into sentences of five to six words. During this period we put a lot of hard work into supporting Kasima's speech at home.

By being the first person to undertake speech therapy with the aid of a hearing device in Leicester Kasima became a pilot study, which due to the overwhelming success of her interaction, many other families began to engage. Over the years I spoke to numerous families encouraging their participation. For me as a parent I have seen how a cochlear implant has increased the levels of participation of which my daughter has been able to engage.

This participation was enforced with the constant support of Kasima's teachers at both primary and secondary School. Both schools encouraged and liaised fully with myself to make any transitions as smooth as possible. The teaching staff used Kasima and her implant as a highlight to what is achievable, not allowing her disability to act as an excuse for her to fail.

A major contribution to all of this is Mrs B who is a specialist teacher of the hearing impaired, she was the first person to guide and support us with the cochlear implant. After a short consultation with Mrs B we felt any opportunity to benefit our daughters future was the correct way forward, with this we agreed to undertake the tests to see if Kasima meet the criteria of the implant. Over the years Kasima has gradually worked her way through junior and secondary school, having just completed her G.C.S.E's achieving and A* for Art and Design in which Kasima has a special talent. She also obtained two B's and a D, which is an outstanding achievement.

In September 2004 Kasima started Full Time College enrolling to undertake a BTEC National in Art and Design. In summary as a family the cochlear implant has been an inspiration to my daughter and to my family. The channels and avenues Kasima has been able to access with the support of the family and outside agencies has been amazing.

I would like to take this opportunity to thank everybody who has been involved at whatever level over the years, your constant support and help is greatly appreciated.

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Michael's story

In 1988 at 3 years of age following losing my hearing due to meningitis I was implanted with a cochlear implant, which after a lot of hard work and support from many people has benefited me greatly.

I began my education in a school for the deaf when I was three and gradually continued my education in mainstream. An award I'm very proud of is gaining a " Civic Citation" for the

progress I have made in mainstream school. I enjoy my part time job at ASDA where I have worked for over two years gaining skills and experience in many areas of retailing including having sole responsibilities for bicycle assembly !!!

Recently I have been involved in talking to young deaf people and their parents and giving the implanted person's view at conferences. I gained three 'A' levels and I decided to study for a degree in Design Technology. for industry straight after the summer. Though I was a little apprehensive I really was looking forward to starting a new life away from home and supporting myself! I now believe it was a very good choice as the note takers were a great help! I now have a good circle of friends who I regularly go out with to the union and the clubs!

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