



# A WORD FROM THE WISE

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Children, young people and  
parents whose complaints  
the OCO has dealt with  
share their stories.

The following stories are based on interviews carried out in February 2015 with children, young people and parents whose cases have been examined or investigated by the Ombudsman for Children's Office. The names have been altered to respect the privacy of the families in question.

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A  
WORD  
FROM THE  
WISE

# Foreword

It is a great pleasure for me as Ombudsman for Children to publish *A Word from the Wise*.

At the heart of every case we investigate there is a story. A story that is part of, and may have had a profound impact on, a child's life.

Behind all the children's rights issues our society grapples with, there are stories. But sometimes the lived experiences of children and their families – the reality of the challenges they face – do not gain the prominence that they should. And nor do their voices.

The purpose of *A Word from the Wise* is to have those voices heard, loud and clear.

My team and I have been honoured to support a number of children and young people whose complaints to the Ombudsman for Children's Office (OCO) have raised significant children's rights issues to share their stories with us, so that we could in turn highlight these stories to the UN

Committee on the Rights of the Child.

As such, this initiative is in keeping with my positive obligations as Ombudsman for Children to consult with children and to highlight matters relating to children's rights and welfare that are of concern to children themselves.

The first-hand accounts contained in this publication illustrate some of the difficulties faced by children and young people in a way that the OCO cannot. The stories demonstrate young people's strength, tenacity, pragmatism and keen sense of justice. They add to the many stories that the OCO has heard from children and young people over the last ten years, including children living in very challenging circumstances. And like previous stories, these current stories demonstrate how listening to children and young people presents a vital opportunity for us to learn from them. So we can do better by them.

These stories also demonstrate the determination of parents to

achieve the best for their children,  
to enable them to have all the  
supports they need to grow up,  
thrive and live with dignity.

I am very grateful to the children,  
young people and their families  
for their generosity in sharing  
their stories with us. One of the  
common threads running through  
their contributions was their  
desire that no other children and  
families should encounter the  
challenges they faced. It is my  
hope that *A Word from the Wise*  
will make a positive contribution  
to making that a reality.

**Dr Niall Muldoon**

Ombudsman for Children



## ROSE, TRACEY AND KEITH

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**Rose contacted the OCO in May 2014. Her complaint concerned the provision of housing by the local authority and how the local authority addressed her family's homelessness.**

The initial complaint concerned the lack of provision of suitable accommodation for her children, Tracey and Keith. Rose told the OCO that she and her children were sharing a house in a Dublin suburb with her two brothers, one of whom had a pitbull dog which bit her daughter. Tracey was hospitalised and needed surgery. Rose also said that she was unable to use the washing facilities in the house as the bath was in a state of disrepair.

Rose said that the local authority told her that she could no longer stay in the house with her brothers, due both to the concern arising from the dog that bit Tracey and because she did not have permission from the local authority to reside at that

address. However, at that time the local authority had not provided the family with any alternative accommodation. Rose, Tracey and Keith became homeless.

Rose said that she and her children were placed in unsuitable emergency homeless accommodation. The family was then granted housing priority but difficulties were experienced in the processing of the application. The family was then penalised for anti-social behaviour which had occurred four years previously.



## Rose's story

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**I believe every child has a right to a proper home. Every child has the right to have a warm bed and food and a safe place and running water. My daughter Tracey is nine and Keith is seven. They suffer because of the way the Council has treated us. I mean, look what they've been through. I'll face up to my responsibility but they shouldn't be punished for my mistakes in the past.**

When we were evicted we had no choice but to move back into my ma's council house. There was no running water. No heat. The ceiling was falling down. My brother was an alcoholic, the other one was on drugs. His pit-bull dog bit my daughter's face. The kids saw things there no child should see.

The next place we were in was filthy. It had a blood stained mattress. Where we are now is nicer but it's not good for the kids. They have to share a room. Tracey is nine so they have to change in different rooms. There's no privacy

for any of us.

It's not just that. I'm sure they feel my stress and worry. I get very low sometimes. There's no sense of stability with all the moving. My kids' childhood is being damaged.

I know I've made mistakes. I have to live with that. But I've paid for them. My children shouldn't have to. I had a tough life growing up and I lost my ma and da when I was young. I know how hard it is to grow up in a tough situation. I want more for my kids. I've got my life back on track and that wasn't easy. I don't have addiction problems now. I don't do anything anymore except mind my children. I'm just a normal person now.

But they can't be normal children. They can't grow here. They can't have friends over - it's not allowed. They've no room to play inside and I'm worried sick about letting them play outside because it's dangerous. It feels like they're making an example of us - of my kids.



They're great kids. I'll do anything for them. Even though they've been through so much, I never had a problem with them. She's top of her class in school. He loves his sport.

They deferred me on the housing list for a year for something I did in the past. But I'm a different person now. I won't be housed for a year. Another year in my life is one thing. But another year in a child's life?

It's so hard to get anyone to listen and understand. They've never spoken to the kids and heard what it's like for them.

I think there should be a special way of helping families with kids. They should be looked after. It should be, I don't know, more of a caring thing not a paperwork thing. They should look at it from the point of view of the kids. A way of fast tracking families. Have a care plan. And good information - explain what's happening and what's going to happen. Clarity, that's the word.

The emotional side is a nightmare and that's not taken on board. I'm on depression tablets. I remember telling the children we were moving here and when we moved in Tracey said 'Mammy are we still homeless?'

She knew. This isn't a home.

### Tracey's story

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I don't have my own bedroom. We have bunk beds. I have my teddies.

It's freezing. Sometimes in the mornings we get our blankets and pillows and move into mammy's bed. But we're never late for school.

This isn't a normal house. Cos we're not allowed bring friends here. We're not allowed outside when other people are out there. I've never had a sleepover with friends since we came here. When I imagine a proper home, it would have carpet up the stairs. When I close my eyes our kitchen is a normal size. It has a glass fridge. The sitting room has a three-seater couch. There's a fire

in each room and it's cosy.

Upstairs I'd like three bedrooms.  
And two bathrooms. All the rooms  
have closets and heating.

I imagine a front garden with a  
dog. At the back there's a porch  
with chairs and a table. It's all  
glass and sunny. There's a back  
garden too with a trampoline - oh,  
and an apple tree.

### Keith's story

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It's freezing. That's why I have this  
furry blanket. I share it with my  
mam and sister. I don't like when  
people bully me.

We have no upstairs. I've no  
space to play except in my room  
but that's full of clothes. I'm sad  
cos I can't have a dog here. The  
apartment we were in before was  
stinky and smelly. The people  
upstairs used to fight. One day he  
battered the pregnant girl outside  
our front door. We couldn't get  
past.

When I think of the house I'd like  
- OK, in the sitting room there's a  
doggie drinking water. The telly's

on. Upstairs there's a black and  
white stripey rug in my room. I've  
two beds so my friend can sleep  
over. I've pictures on the walls - I  
can't have any in this house.

In the garden there's a flower pot  
there and a flower pot there. We've  
two guard dogs, a trampoline and  
a bouncy castle.

If we had that house we wouldn't  
have to move all the time.  
Mammy's cried over that.

## MIKE, JEN AND CIARA

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**This complaint was brought to the OCO by Mike and Jen, whose four year old daughter Ciara had significant motor problems resulting in a diagnosis consistent with cerebral palsy. An application for a powered wheelchair was made to the Health Service Executive (HSE) but was refused. One of the parents' main concerns was that Ciara was refused the powered wheelchair using her age as the sole criterion, without any assessment of her ability and without taking into consideration recommendations from the professionals caring for her in regard to her needs and capacity. The officials in question also made the decision without meeting Ciara.**

Ciara's parents also stated that there was an inconsistency between their local health office's policy and the policies in operation in other areas. Specifically, they indicated that their area would not consider applications from children under the age of 7, whereas children of a similar age and level of need in other health office areas had received powered wheelchairs.





## Mike's story

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**Ciara was born with a number of acute conditions which meant she had a lot of problems with mobility, coordination and she also had a serious abdominal disorder. We were worried sick. It was a difficult time but we just took it day by day.**

Ciara is really bright – she’s doing great in mainstream school and there’s nothing at all wrong with her brain. But she needed a lot of supports and assistance with certain things. She was professionally assessed and she got a manual wheelchair which was great for a while.

But we quickly realised her childhood was limited in certain simple but important ways. Ciara has very little strength so it meant that she couldn’t push herself. So you can imagine when she was playing with her friends outside, and they were running around or playing on the grass, well, she’d be isolated. There’s nothing worse than seeing all the other kids playing and your own kid losing heart and going home.

You just want to make it right but you can’t. Yes, we could help her – and we did all the time – but it wasn’t the same as her being on her own, playing independently with her friends. Living her own childhood.

So, it was really clear that from age three, she needed a powered wheelchair. We applied for one and we were refused by the local HSE office. The reason they gave was that she was ‘under the age of reason’. They said the age of reason is seven years old.

She had been attending Enable Ireland\* and doing great because of their services. She had actually been training in the use of a powered wheelchair and passing all the exams. So I couldn’t understand their decision for a number of reasons.

First, how can they refuse it if they haven’t seen for themselves and talked to Ciara? No one could tell us what they meant by the ‘age of reason’. Surely that varies with every child and every condition?

Also we knew that they had sanctioned a powered wheelchair for a child the same age as Ciara in another area. So why not for Ciara? I argued so many times the logic of the situation but just got a blanket 'no' - the decision had been made.

Our kids are the lights of our lives and Ciara is one amazing girl. Anger doesn't even come close to describing what I felt, that we weren't getting any answers or understanding. She was meant to be starting school. She needed her chair badly. Wherever we went we just hit a wall.

Enable Ireland informed us about the Children's Ombudsman. It made such a difference when they told us 'we're going to investigate your case'.

When we saw the HSE Office's reasons for refusing Ciara, what they said in writing really shocked us - it's there in black and white. They said we were living in a house that wasn't wheelchair accessible. Completely untrue. They said local transport was not accessible but every bus in

the area is wheelchair accessible. It gets worse. They said Jen wouldn't be able to take care of Ciara in a powered wheelchair if she had a new baby in a buggy. They said we were living in a deprived area with a lot of lone parents, drug-using families and they were afraid Ciara would give people a lift to the shops in her powered wheelchair.

I've worked all my life. We are a quiet, responsible family with great neighbours. So we were hurt and furious because as far as we were concerned this wasn't anything to do with meeting Ciara's needs and rights. This was just discrimination and prejudice. And a horrible judgment of us as a family.

We won in the end but we were three years fighting for Ciara's powered wheelchair. For me that's not just having to spend three nightmare years of our lives fighting the system for something badly needed. More importantly, that's three years out of Ciara's life. Three crucial, life-changing years. There's no doubt in our minds: she missed out big time.



Basically, the way I look at it is, they wanted us to wait until she was seven to have a childhood.

For kids with disabilities and their families, it's a constant fight to get what you need. It was a nightmare for us and I wouldn't want any other child or family to go through it. The HSE say they've changed their policy but we don't know. We hear of other families still having similar battles.

We never hid anything from her. She knew we were fighting the case. We know we'll have more battles. What happened shouldn't have happened. If it happens to anyone else, they should be given clear answers. It should be the same level playing field for every child. There can't be two different standards or different rules just because you're dealing with a different person in a different office. There was no appeals process because they just pushed us back to the original person.

We definitely didn't get a hearing. Ciara certainly didn't and she deserved it.

Life now? Once we got the powered wheelchair, Ciara was able to have a childhood. She's doing great in school. It's positive now that people are asking to use Ciara's case to win their battles. It's great psychologically to think that we can help other families.

## Ciara's story

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It takes a lot of explaining to tell my story. I'm proud of my mam and dad and what they did for me. The powered wheelchair changed everything for me. I could play with my friends. I could even go across the grass – the manual one gets stuck. If we go out on walks I have independence, I can go on ahead myself.

School is good. I've good friends. I'm the first kid with a chair. I got 10 out of 10 for spelling. The SENO (Special Education Needs Organiser) and my SNA (Special Needs Assistant) are brilliant. I like her cos she helps me. And I need lots of help.

I get botox twice a year in my legs. I have a walking frame and I'm getting stronger on that. I done a

charity walk for a friend of mine. He needs a big operation. I got nearly €4,000 for walking from one end of the green all the way to the other. I was tired. I had loads of sweets after to celebrate it. I'm very proud for doing that.

It's been hard sometimes. I've learned that every feeling is OK. It's not bad to feel sad or happy. If I'm angry and frustrated I'll go outside and scream. Things could be worse than what they are.

I want to be a tooth fairy when I grow up. Then I won't need a wheelchair cos I'll be flying around the place.

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\*Enable Ireland is an organisation that provides services to children and adults with disabilities and their families

## SARAH AND DANNY

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**Sarah contacted the OCO in relation to her 16 year old son, Danny, who had sustained an Acquired Brain Injury (ABI) following a car accident at the age of 15. The complaint related to a lack of dedicated services for 13 to 17 year olds following an ABI, a lack of organised support available for Danny and his family, and the lack of a focal point with responsibility for providing assistance to families in these circumstances.**

The complaint set out the difficulty and challenges faced by Danny and his advocates in seeking to secure psychiatric and psychological supports and services on his behalf. The complaint highlighted that the majority of the organisations that Danny's mother contacted would be in a position to help her son if he was under 13 or over 17 years of age, but that none would take responsibility for his care at this age.

The complaint therefore highlighted a potential gap in health services for children of a certain age with ABI.





## Sarah's story

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All our lives changed completely that day. My son Danny and husband Gavin were involved in a serious traffic accident. Danny was 14 years old at the time. He sustained a very serious head injury. He had a number of physical injuries like a fractured jaw and fractured skull. But he also had brain injuries that acutely affected his coordination, emotions, balance and ability to rationalise. It was a dark time for us all.

Danny was in an induced coma for 48 hours. When he woke he was completely disorientated and a little psychotic. He couldn't rationalise what had happened. It was hard for him to adjust over the next few months. He had to learn everything from scratch again. To walk, talk, to re-learn his coordination.

The big turning point was something he said to me that totally shocked me. We were coming back in the car after a medical appointment. He said he'd had enough. He was talking

about suicide. I had to try to control the panic and worry. I said to him 'can you give me a few days to organise things?' That was the day I effectively became his case worker. I took a year out. And looking back everything was such a battle, it was our only option.

That's also when the nightmare became very clear. He had medical care but there was no psychological and emotional care available. We found out there are services available for children under thirteen and for young people over seventeen. Danny was fifteen at the time so he didn't fit any category. To me that was wrong. It was discriminating against young people like Danny.

You can imagine what a panic I was in. I've made an important promise to my son and I'm faced with a nightmare situation: there are no services for him.

He arrived home from hospital in a wheelchair. He was completely different. He had gone from an active, bright, confident, sports-mad teenager and now he couldn't sleep on his own - he had to sleep

with me. He was stressed and anxious. He would time me going to the bathroom.

We had to fight to find any help. Calls, letters, emails. Lots of research. We contacted everyone who might be able to help. Friends and family lobbied TDs\*. The experience changed me. The unconditional love you have for your child, it's so powerful. I would have done anything. I became a person I didn't recognise.

But the thing is, parents shouldn't have to become campaigners and case managers for their child. It's hard. At the very time you're at your lowest – when your son has had a life-threatening, life-changing accident – you have to be at your strongest.

I also discovered that there's no support group for families coping with Acquired Brain Injury in children. It would have been so helpful and reassuring to talk to other parents and children who had gone through the maze we were trying to find our way through.

In the end we managed to get help. But it was help in different places. Paediatric psychology in one location. Speech and Language Therapy in another. Occupational Therapy somewhere else. Psychiatry in a different place. It was the kind of help where people went out of their way to bend the rules.

It is a big testimony to Danny's character that he got through it and went from strength to strength. I had to apologise to him one day. He wanted to change school. He had gone back but he felt his relationships with friends had changed and that the school had set low standards for his ability to do well. I was against it – another huge change in the middle of everything. But he was absolutely right. He thrived in the new school.

If someone had another brain injury in the morning like Danny's, would things be better and different? Things have to change. First, there have to be accessible services for Danny's age group. I think there should be one person or office that



could coordinate all the different services. A mother shouldn't have to case-manage their care. Schools should be educated to understand brain injury and how best to support pupils. The medical professionals should be informed also and Special Needs Assistants should get some basic training. We also need a support group for the families.

You shouldn't get care for your child based on your resources or your powers of persuasion or your location or your ability to lobby.

## Danny's story

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I can't believe the struggle mammy needed to go on just to get the services I needed put in place. A young person's brain recovers faster and better than an older person's. The quicker you get the services in place, the quicker you get the most from your recovery. You shouldn't have to waste time fighting.

Other people aren't as lucky as me. If I didn't have mam fighting for me, I don't know what I'd have done. She had to give up her job.

Not every family can do that.

I started a petition in all the schools in my county calling for services for teenagers with Acquired Brain Injury. That escalated into presenting the petition in the Dáil\*\*. Then we got onto the TV and radio. My younger brother Leo spoke for the first time about it all. He shocked me. The emotion in his voice. It just proves young people like us have something important to say.

I was so determined to recover. Will I ever get back to sport? That drove me on. I really applied myself to the therapies and it paid off.

Going back to school was tough. I was really looking forward to it. Some kind of normality. Seeing all my friends. But after one class I was exhausted. I felt my friends were minding me too much. I was being looked at through different eyes by the teachers. They just saw me as someone with a brain injury.

So I moved schools. It's pointless saying I wasn't scared, I was. But

it was a great new beginning and people really accepted me. I've made some incredible friends. The teachers are amazing.

I believe young people shouldn't be forgotten. We're important. My younger brother Leo is amazing. He was only 12 at the time and he kind of became my protector. In a way he helped me find my independence again. I remember one day walking down the street and I was holding my mammy's hand. Leo took it on himself to get me to walk beside him in case other lads would see me holding hands with my mother.

I think it's only fair to say that I deserve every chance after what me and mammy went through to provide a future for myself. The scary thing is that someone else will have an injury like mine and they'll come up against the same brick walls.

I'd love if the person with a brain injury would wake up and every service is there available to them and to their family cos the outcome would be much better.

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\*TD stands for Teachta Dála, a member of the Lower House of the Oireachtas (Parliament).

\*\*Dáil Éireann is the Lower House of the Oireachtas (Parliament)

## EMMA

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**This case relates to Emma, a 17 year old whose parents contacted the OCO when she was about to sit her Leaving Certificate\* because they were concerned about the State Examinations Commission’s process for assessing their daughter’s eligibility for the reasonable accommodations of a reader and a spelling/grammar/punctuation waiver for her exams. Emma had a diagnosis of dyslexia and provided supporting documentation from her psychologist as part of her application. The psychologist was of the view that Emma met the criteria for accommodations, yet the tests done in the school indicated that she did not meet all the criteria.**

Emma’s parents were unhappy that such evidence was conflicting and they felt that they had not been provided with a full explanation for their daughter’s refusal of accommodations by the State Examinations Commission. They felt the decision not to provide supports was particularly

unfair given that Emma had required educational support throughout her education since she was diagnosed in primary school. Issues such as those arising in this complaint have been brought to the OCO by a large number of parents in recent years.





## Emma's story

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What I feel is that in all of the events that happened last year, I was kind of forgotten – as a student, as a young person. That was because someone I didn't know, someone I couldn't talk to, someone who didn't know me, made a decision that made no sense. And that decision turned my life, and my family's life, completely upside down. It made my life hell at a very stressful time. And it could have had a terrible effect on my future.

I'm very angry about that. And I'm concerned that the same thing will happen again to other people with dyslexia. It's hard enough to cope with a learning disability without having to fight for fairness.

I was diagnosed early in life with dyslexia and dyscalculia. We got a psychologist's assessment when I was in 5th class\*\*. Because of that I got the spelling and grammar waiver and I was allowed a reader for exams. I was reassessed for the Junior Cycle\*\*\* and I got the waivers again. But then just as I was a few months away from

sitting the Leaving Cert, I was informed that the waiver had been denied. That I'd have to face the exams with no supports at all. All I felt was panic and fear. Disbelief.

Up until this, me and a few other students had the waivers. Some had dyslexia, some just needed help with subjects. And the school was really great with us. They gave us brilliant support and understanding. In April 2013 we did a writing test. In November the others all got a letter saying they still had the waiver. But I didn't hear anything until February 2014 when they said I had lost my waivers.

I honestly couldn't understand it. I knew better than anyone that I needed help. My mam and dad knew it. The school couldn't understand it. It was the first time a child in the school had been refused. My dad was fuming. He said they were basically telling us that I had been cured overnight – a miracle cure. The school couldn't get an answer from the Department of Education and Skills or the Examinations Board.

So we tried to fight it. My parents were brilliant. It took over our lives completely. The school appealed the decision. We appealed it. My resource teacher wrote a letter. We got a letter from the psychologist. We had his report confirming my dyslexia and dyscalculia. We got a letter from the Principal. I wrote a letter myself. All were refused. We spoke with local and national politicians but got nowhere.

In the end there was nothing. I had to do the exam without the supports I was entitled to. It was horrible.

There are a few things I'm really concerned about. The decision was a terrible one. I knew I needed the supports. I'm in Third Level now and I have the supports back, along with other help they believe I need. And I'm doing great because of that.

The other major issue for me was the timing. Why make a decision like that a few months away from the most important exam in my life, one that would determine my choices in life? It was going

to affect every subject but if you fail maths you're in big trouble in terms of choices for college. Luckily my dad found me a maths grind which helped and I passed, but only just.

The biggest problem was that the clock was ticking. And every question my parents would ask, every letter they'd write, it all took time. And time was one thing I didn't have. I shed tears of anger. It was all too late before we were given a name of the person who made the decision.

From what I can see they just took the result of one test above all the other evidence, appeals and experts. And I've no idea why they did that.

The reality is I did suffer badly because of it. My family suffered. I guarantee I would have done a grade better at least in Maths, English and History. The thing is, I went into those exams with a sense of panic and stress. Can you imagine? Every day I had to see my friends who were given the waiver going into the exams with no stress and full of confidence.



It just made me feel low and panicked.

I know things can go wrong and mistakes can be made. But when that happens, there should be a simple way of correcting it. Or even a way of finding out why the decision was made so you can give your side. I feel I never got the opportunity to make my case.

The timescale gives you no chance. You go to the same people to appeal. That's not right. I think there should be one independent person you can go to. And an easy process. They should give you a clear reason. There should be some kind of emergency appeals process if things happen so close to exams, but they shouldn't refuse you so close to an exam in the first place.

My dad says we were a family that had a brilliant supportive school, experts on our side and the energy to fight for what's right and we still couldn't get anywhere. What about people who don't have that?

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\*The Leaving Certificate is the final State Examination, generally sat by students after five or six years of post-primary education.

\*\*The penultimate year of primary education.

\*\*\*The Junior Cycle culminates in the Junior Certificate, a State Examination generally sat by students after three years of post-primary education.

## LIZ AND JOHNNY

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**The complaint was submitted to the OCO by Liz on behalf of her son Johnny, then aged nine, who attended a mainstream national school. Johnny had a number of medical difficulties which had been identified by professionals working with him, though no specific diagnosis had been identified at that time. These issues were causing Johnny difficulties in school with hand writing, fatigue, fine motor coordination and concentration levels.**

The complaint made to the OCO related to the recommendation of the National Council for Special Education (NCSE) and the subsequent decision of the Department of Education and Skills to refuse an application for assistive technology made on Johnny's behalf. Although the application was made with supporting documentation from a range of medical professionals, it was refused on the basis that there was no specific diagnosis for

Johnny. The projected cost of the assistive technology - consisting of a laptop and appropriate software - was in the region of €1000.

The Department stated that the Scheme is designed to provide technology to support children with a disability and distinguished between an assessed disability and a medical condition. As there was no specific diagnosis at the time, the application did not meet the criteria in spite of Johnny's identified need.



## Liz's story

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Johnny was nine when all of this happened. He has a series of complicated conditions that affect him in a major way. Problems with pain in his limbs, unstable joints, mobility, intermittent paralysis and poor concentration. He often needs a wheelchair.

All I wanted him to have was a good education and a chance like other children. Nothing else.

Looking back I know that this wasn't just a battle for a laptop, it was about his right to be a student like anyone else. It was about the impact of the laptop - or the lack of it - on our entire family.

I got a letter from hospital saying Johnny had a number of serious problems and conditions but they needed time to find out exactly what it was. They said at that stage they had no diagnosis for his condition.

From early on he was having problems in school. He couldn't write properly and he'd get severe pain in his arms and hands. He'd be shattered at school and doing his homework.

In third and fourth class Johnny's condition got worse. I was at my wits end. He was tired, he'd cry in pain, he was stressed out. It was clear he needed help.

He was professionally assessed. The report said he definitely needed a laptop and he would also need it through secondary school. It would be a great help also for homework.

So we applied through the school to the Special Education Needs Organiser, the SENO, for the laptop. I couldn't believe it when the SENO turned Johnny down because she couldn't match his 'no diagnosis' to a series of tick box conditions on a form.

Things just got worse. He was stressed. I was stressed. The whole family was affected. Johnny was struggling at school which meant we'd be struggling at home.



Meanwhile we were still waiting for a neurologist, for more medical help, for a wheelchair. I had to give up work. That was my wage gone. I was angry because they wouldn't get him a laptop he badly needed and was fully entitled to. I was determined to get justice for my son. I went to the newspapers. I wrote letter after letter.

All through it, I was feeling guilty. I was so frustrated. I'd cry every night. I felt I was failing my son. He was saying 'it's not your fault mam'. But I brought him into the world. I will fight for him and his right to have a proper education. I'd get up in the morning. I'd take a look at his face and I'd say 'right, this day is for you Johnny.'

I trawled the internet and found the Ombudsman for Children's Office. Without them I wouldn't have got through it. They were the very first person or organisation to speak to Johnny and to listen to him.

The morning the OCO report on our case came in the post, I was thrilled they found in our favour. They believed us. It was a

huge turning point for us. I said "Johnny, we won!" This load lifted off my shoulders.

But we still had a battle on our hands. The SENO wouldn't answer the phone or return my calls. So we went on the TV news. Newspapers. I made call after call until I found someone senior who sanctioned the laptop. We had it within a week. We had his school books on disc.

He's in secondary school now and it's a fantastic experience. It just shows how simple it could be if the school had listened and the Department had listened and used common sense.

Why did I have to go to such lengths to get my child what he needs and deserves and has a right to? It's hard but it's worth it. I watched my child cry so many times.

The irony is that no parent wants to label their child. No one. You shouldn't have to. But then, when you have to label them - and you can't because there's no diagnosis - they shouldn't be penalised.



Looking back it could have been so easy. They should have accepted the word of professionals and not looked for a diagnosis that ticks a box. There should be flexibility and common sense when someone can't be diagnosed. It should be clear who has responsibility and we should be able to talk to them like human beings. They should have listened to me and Johnny.

No one had ever listened. My heart was broken. I'd do anything that would raise awareness and change things for him. Now I'll do what I can to change things for others.

## Johnny's story

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I remember it so well. Trying to cope in school. I just wasn't able to get everything done. I'd be pumping with pain.

The whole thing was crazy. No one ever really listened to me or understood what I needed in school. We had to fight for a simple laptop from 4th to 6th class\*. It took about 18 months. It was mad. They drove me home

from school one day so that I could go to the bathroom because I didn't have a Special Needs Assistant assigned to me. Two of them in a car with me.

In the school once a month they had an award ceremony. Best handwriting. Best improver. I was always ignored.

One day at a meeting my patience went and I let rip at the teachers. It was building up for ages. They tried to stop me talking but my mam said to them they had to listen because they hadn't before. So they did. But then a while later, as a treat, they were allowing the class to see a movie but they said I couldn't go because I had been disrespectful.

When you struggle in school it affects other things, not just your subjects. You feel isolated. Not having the help I needed did lots of damage. It stopped me from making good friends. From mixing.

I felt so bad about everything. I didn't want to be the cause of upset. I didn't want stress for

my whole family. But I felt like I was being punished for having a disability.

Now that I have the help I need it has made such a difference. I mix a lot more now. It has even changed things for me like that, not just school work. I'm more confident. I'm glad they found out what was wrong with me: Ehlers-Danlos Syndrome. It's hard but at least we got a diagnosis.

Having the laptop makes things a hell of a lot easier. A homework assignment that took 2 hours now takes me 30 minutes. I can copy stuff down in school in time. I can draw diagrams on it. I can do my exams on it. My self-esteem is up. No bullying or being made fun of. It's a long way from the time I popped my shoulder out from carrying the schoolbag of books.

It was amazing to be listened to. It made such a difference to us. I hope it helps others.

The best thing is knowing we did something. It's knowing we didn't back down. No child should go through what I went through. It

can happen once but never again. I'm proud we won our fight. I'm proud of my mam.

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\*The final three years of primary education.

## KAYLEE

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**The OCO was contacted by Kaylee, a 19 year old care leaver, in relation to the lack of aftercare accommodation for herself and her infant son.**

Kaylee explained to the OCO that, due to difficulties in accessing suitable accommodation, she and her son, who was not in care, have remained living in a children's residential centre for mothers and babies. While Kaylee appreciated that she had been able to remain in the residential centre, she felt that it was not an appropriate home environment for either her or her son. She advised the OCO that, while living as an adult and a mother in a children's residential centre, daily reports are kept on her and her child and she is obliged to follow the rules of the centre even if they are not age appropriate.

Kaylee also told the OCO that she was on the local authority's housing list but did not have any priority listing. She understood that her options were to remain in the children's residential centre or to present as homeless in order to gain priority in this way, which she did not consider appropriate for her or her son. She felt that other young people leaving care had more options than her.





## Kaylee's story

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**I'm 19 years old now. And my little son Alan is two. I fell pregnant with Alan when I was 17 and I was living in a residential care home. So I moved to a care home for mothers and babies. And I loved it there.**

But I was turning 18 and you're supposed to leave when you're 18. But there was no after care unit or placements for someone with a baby. Other kids from residential homes have aftercare placements and aftercare services. But there isn't any for girls who have babies.

I don't think it's fair that girls who have babies are out on their own. Because now it's about my baby too. I didn't realise it until I became a mother myself. And then a load of things clicked. Like the importance of attention. Making sure kids get the love and care and praise they need.

You see I wasn't treated very well. I was in and out of care my whole life. And I'm really angry at the authorities and the health service.

They screw up.

Like my ma and da were both on drugs for a long time so me and my sisters and brother were put on a full care order. We went to my auntie and uncle. And they were great. They really looked after us. Kept us in school and all.

But then we got sent back to my ma. That should never have happened. They thought she was doing ok and on the methadone, but she wasn't. And like we were just kids, we wanted to be with her. And she was saying she loved us and all. So we went back.

I mean I witnessed things when I was a child. Me ma taking drugs. Violence and murder. If I didn't get into the proper care I'd probably be back there now with four kids and be doing drugs at the weekends.

But after a few years I got taken off my ma. The inspector reported us for missing school and I was put in with a few different families before they sent me to a residential care home. That was a lovely house. And things started



going better then. I went to school and all there.

I met Ben when we were 14. We're still together now. And I fell pregnant when I was 17. So I moved into the mother and baby unit. And it was great. They even let Ben come and spend time with the baby. I learnt things there. You had to pay rent each week and learn how to budget for you and the baby. It was the first time I learnt anything like that. And I'm good with budgeting now.

But I was only there about six months when they said I had to leave. Because when you reach 18 your time is up. And I was used to having people around. Someone to wake up to – the managers, staff and other girls and their babies. Now I'm on my own all day.

I think there should have been some step-down service. Some kind of bridge between the care home and the real world. Other kids I knew from residential homes got after care services and training. Some of the aftercare places are literally next door to the residential home. But because I

had a baby I was on my own and trying to find some place to live. And rents are crazy. And most places are real dives and won't accept rent allowance.

I was almost going to put myself homeless as well. Alan was only 6 months old and I wouldn't put him in dangerous hostels. I wrote letters to everybody. I wrote 12 letters to managers in the HSE (The Health Service Executive)\*. And they all said there was nothing they could do.

Like I said before, it's just about the proper care and attention. Like when I was in the care home I went to school and, in fairness, I did really well for somebody with no pattern of going to school. But when I got pregnant I had to leave at some point because my uniform wouldn't fit and it was hard to walk around school like that. But one of the teachers used to pop around to me to help me finish assignments. That's someone who cares. So I did my Leaving Cert\*\*. I'm very proud of that.

You just need a little help at the right time. A stepdown living

space. Just some small houses attached to the mother and baby unit. That way you could link in for some support and advice and practical help when you needed to.

I found it hard to get anyone to listen to me. I think they all should have somebody who was in care telling them what it's really like. They should be listening to the people that have been through it.

I'd rather work than be on social welfare. I don't want to be in voluntary housing for the rest of me life. I want my own house. I'm real proud of myself. I've gone through hell and I've survived. I've a lovely son and I'm going to care for him the way others didn't care for me.

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\*The functions of the HSE with respect to social care have been taken over by Tusla, the Child and Family Agency.

\*\* The Leaving Certificate is the final State Examination, generally sat by students after five or six years of post-primary education.

## RITA AND CAIT

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**The OCO received a complaint from Rita, whose 15 year old daughter Cait had been admitted to a casualty department in a major regional hospital following a second attempted suicide.**

Cait was then transferred to an adult psychiatric ward at the same hospital, pending a place becoming available in a more appropriate adolescent mental health unit. At the time of contacting the OCO, no place in the adolescent unit had been made available. Cait had been placed in the adult ward for two weeks and her mother complained that this was an inappropriate setting, that it was placing her daughter at further risk and that it was not in her best interests.

This complaint was one of a number received by the OCO in recent times relating to the placement of children with mental health difficulties in inappropriate adult units. These complaints have highlighted difficulties nationally and regionally in regard to children accessing appropriate mental health placements and supports.





## Rita's Story

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It was 10.30 at night. I was watching TV. I heard Cait screaming. She had overdosed on paracetamol. This was her second suicide attempt in a short space of time and the planned nature of it really frightened me.

She kept saying 'I'm sorry, I'm sorry'. But this time was different. It was the sense I could have lost my beautiful girl. She was a very determined person. The next time she might succeed.

I became aware Cait was in trouble when she wrote a letter to me months before. It contained some very dark things. She talked about being inadequate. Low self-esteem. Problems with friendships. Problems with eating. Thoughts about suicide.

You can imagine what a crisis like this means to you as a parent. The shock. The guilt. The sense of failure. The worry. But in those moments it's all about being there for the child you love so much. I knew I had to show her action was being taken. I know that people don't just talk about suicide for no reason.

And I suppose over the course of Cait's struggles, this was my mission: to ensure that I kept her as safe as possible and that she received the very best care possible. Two suicide attempts later, I feel that I was prevented from doing that by a system that's broken and inadequate and sometimes not there at all, especially for a child.

Looking back there were several key moments when Cait was not receiving what she needed or was at risk. Our first engagement with the services was through our GP (General Practitioner). That was a good experience. She was understanding and decisive. She referred us immediately to CAMHS (child and adolescent mental health services).



We got an assessment quite quickly. But CAMHS is underfunded and understaffed and access is inconsistent. All they could offer us at that time was six weeks of counselling after which their assessment was 'we think she's OK'. But there were two suicide attempts during that time. I believe CAMHS doesn't have the resources to deliver the service they need to, and certainly not out of hours.

The suicide attempts meant our next interaction was with the Accident and Emergency Department. A&E is not a proper facility for a child who has just attempted suicide or who is fragile. There is no one available from the Psychiatric Department out of hours so they have to bring in services from CAMHS, which can take 12 to 15 hours. In a crisis, with nowhere else to go, people will present to A&E. This is as unfair on A&E as it is on the young person. It's already overcrowded and the staff don't have the time or training.

Cait was next let down by the system when she had no

alternative but to be admitted to the adult facility. Because she was a child, she had to be segregated and kept in her own isolated room. I know it's for her own safety but it's not at all healthy. Despite the efforts of some great nurses and staff, for Cait, it felt more like a prison than a caring or healing facility.

There was no clarity or thought-through strategy at any stage. I'm lucky, I knew what Cait needed. But what about families who don't have the knowledge or confidence? Because crucial services aren't available at key stages, children could be in grave danger.

Every parent knows their child. I believe in Cait. I know she will get through it. I know Cait is extraordinary. I remember her as a toddler. Fiercely determined. Confident. Knowing what she needed. Finding her way into my bed every night. The services didn't see that she had that strength in her to be tapped. I knew it hadn't just disappeared. Thank God it's back now with her recovery.

Sometimes I felt that the care we received was dictated and blunted by the fact that the services aren't there and the staff isn't there – services designed for children, that listen to children and that have high expectations for them. At one crucial point the only help the Chief Psychiatrist for the area had for us was to advise us to go home and get better. That was because there was nowhere to refer us to.

The reality is that across the country, available services are patchy and inadequate. There is a lack of residential facilities for young people. We discovered only two – one in Dublin, which only takes people with medical insurance, and one in Galway. Both have long waiting lists. There is nowhere for a young person in crisis to go except to an inappropriate adult facility. I believe if there was such a crisis centre where they could go, this would alleviate the problem.

We came across some fantastic people – very dedicated, very skilled and very caring – but so many are demoralised. My worry

is that this kind of helplessness makes its way into how the system deals with patients. I felt they had low expectations for Cait herself and for her recovery. That's not good.

And look, they can't say they're taking children's rights seriously if they're forcing children into inappropriate adult facilities or basically making the problem go away by sending the message to families: go home and be a good parent.

Cait has recovered. Strong as she is, she didn't do it by herself. She has a brilliant female psychologist now from CAHMS who has worked consistently with her throughout this year and continues to work with her. I do believe great work has been done by health promotion campaigns in helping to destigmatise mental illness and urging people to get help. This shows the system can work with the right policies, resources, fit-for-purpose facilities and adequate staffing.

## Cait's story

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The first time I attempted suicide I think my real message was 'help me'. But there was no effective help for me. A&E was a nightmare. The adult unit was like prison. The counselling I got from CAMHS wasn't right for me and it didn't work.

When I was in hospital after overdosing on paracetamol I was in bits. It was the worst pain I ever experienced. But I didn't want to go home because I was kind of afraid of myself and what I might do. My mam knew I needed residential. But there wasn't much on offer - just the adult unit.

It was not a good experience being in the adult facility. I was in a room by myself. I was being watched 24/7. I wasn't allowed in the main ward. I couldn't shower or go to the toilet by myself. Couldn't go to the shop - even with my mam. I stopped shaving my legs because they'd stare at me. I was very vulnerable. I'm so self-conscious, I can't stand people looking at my body.

The only exercise available was a treadmill. It was in a freezing cold room. I used it for a while out of boredom but then I just couldn't. It seemed wrong anyway. I had an eating disorder and I lost 3 kilos on the treadmill.

I know myself better than anyone knows me. It wasn't a good place for a young person like me. I was alone. I think it wasn't just the wrong place for me. It was a damaging place for me.

I feel I was let down. I needed help and it wasn't there. But some of the nurses were amazing. We had great chats. That's what saved me. Some of them trusted me. The nurses helped me during that time. Helped my thought process. It shows you what might work if they got it right.

I knew I could get better. My mam was fantastic supporting me but I knew I had to fight all the way for myself too. I'm still here now to prove it. That's when I became interested in the career myself. What if in the future I can help someone? I'm aiming to get into university, to get the points. Even



to make a small difference makes me happy.

I had a terrible experience and other teenagers shouldn't have to go through it. The facilities and lack of staff is kind of a disgrace. People are caring. Lots of them are good at their job but there's not enough of them and not enough spaces for children and no out-of-hours response if it's needed. There should be specific wards for my age. The adult unit can't cope with children. That's not fair to us but it's not fair for the staff either.

I know a lot now about mental health. About the system and its faults. I know myself better now. I have a lot to say for myself in the world and about the world. I just wish the right people had listened at the right time.



The Ombudsman for Children's Office (OCO) is an independent human rights institution established in 2004 to promote and monitor the rights of children in Ireland. Over the ten years since its establishment, the OCO has received over 10,000 complaints covering a wide range of issues affecting children, including health, education, social care, housing and services for children with special needs.

*A Word from the Wise* brings together the stories behind seven cases that have been examined or investigated by the OCO and that highlight systemic issues affecting children in Ireland in some of these areas. The aim of the project was to support children, young people and their parents to share their stories with the OCO so that it could in turn highlight these stories with the United Nations Committee on the Rights of the Child.

