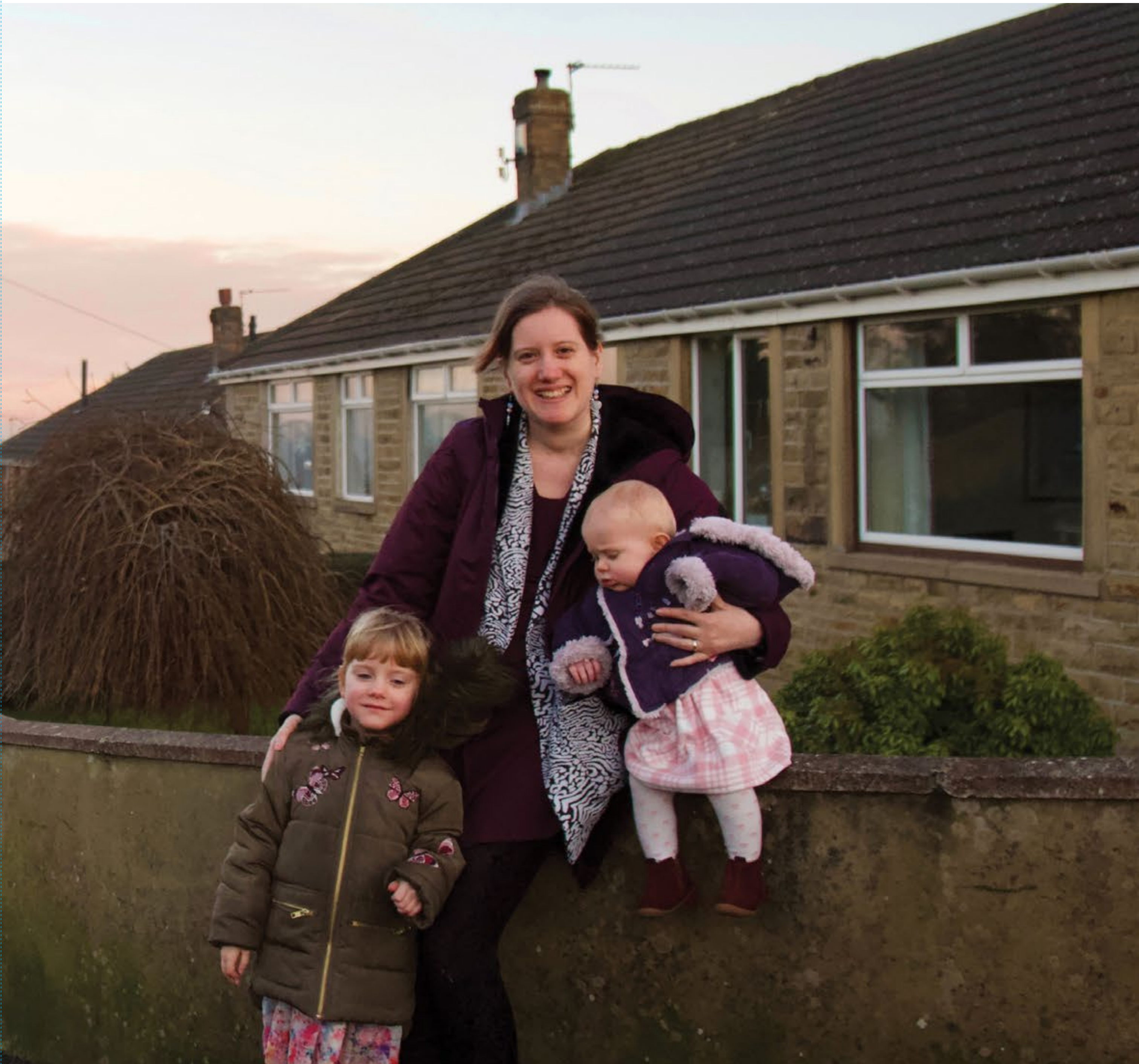
PAIGE

Stories of parents with learning disabilities



PAIGE

Stories of parents with learning disabilities

Part of Mind the Gap's
Daughters of Fortune project.

Writer: Mary Cooper
Photographer: Emilie Flower

For Ruth, Pippa, Alison, Rayne and Willow

It all started with the story of one woman.

It was 2015. The choice of whether to go into motherhood had preoccupied my mind. I doubted my ability to be a good parent. Then one day my friend told me that her sister, who is on the autistic spectrum, was being assessed for parental capability by the social services. I was baffled. Being a new parent is hard enough, let alone needing to prove yourself. Later I found out there are over 300 skills that could be assessed. Mind blown.

It's not just the assessment. Online search had yielded findings that painted a very narrow picture of "parenthood of learning-disabled people". Some stories were sensational and melodramatic; worthy of EastEnders. In others the parents were presented as the faceless and generic *other,* worthy of charitable sympathies. I couldn't even find an image of a learning-disabled person as a parent, just as children. Working for a theatre company with learning-disabled artists, I've witnessed relationships and break ups. Their emotional adult life and reality are as real as anyone's, yet these stories aren't told, as if adult life wasn't for them.

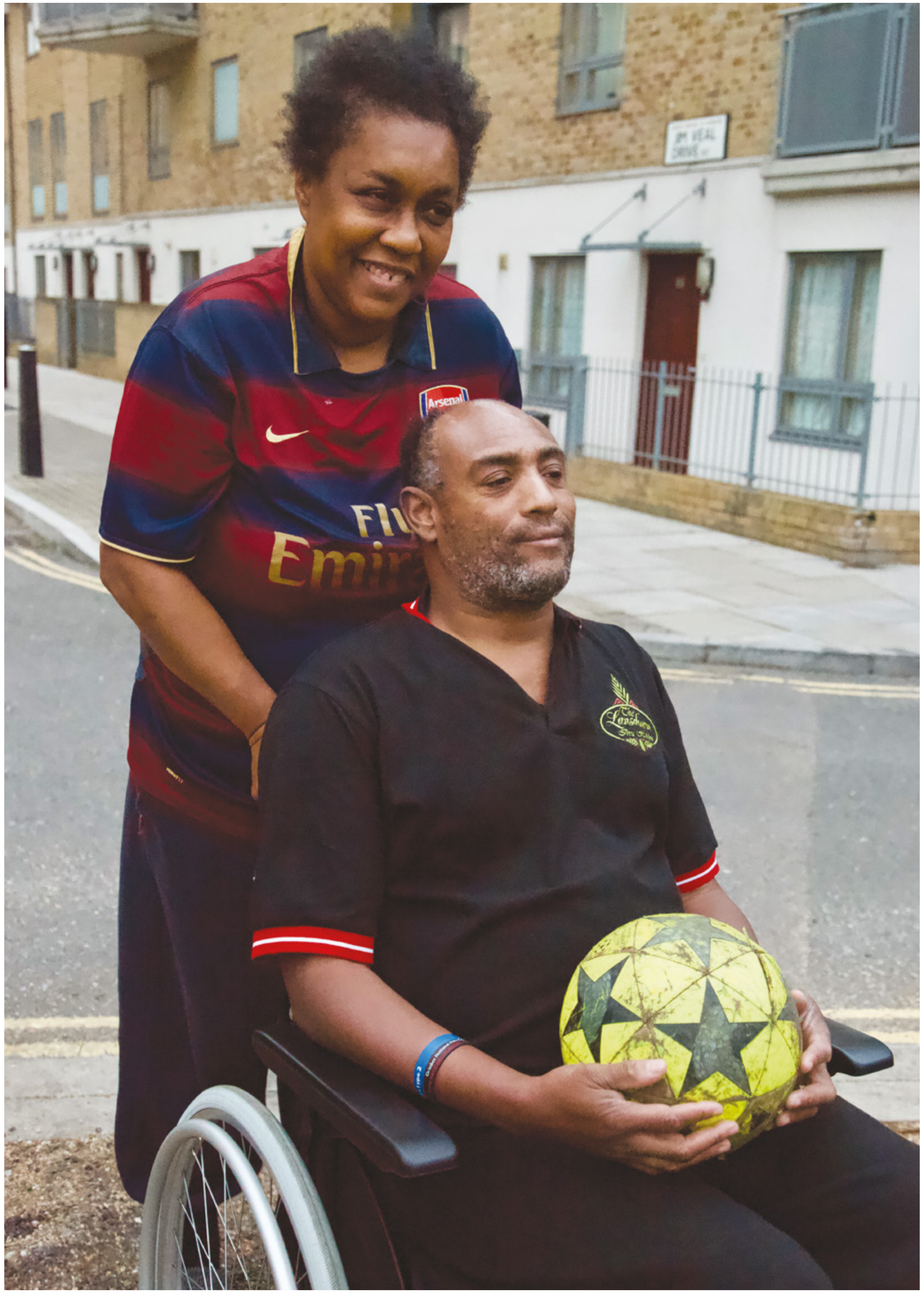
I wanted to change this narrative and that was how the *Daughters of Fortune* project started.

In the past four years the artistic research team, headed by Mary Cooper, Daniel Foulds and Emilie Flower, spoke to parents with learning disabilities to find out their stories. The stories became the basis of three theatre productions, including a large-scale outdoor event that featured a mechanical baby puppet bigger than a double decker bus. Led by Dr. Kate Theodore and Laura Franklin, stories were analysed and research papers published and presented. To date we estimate that over 30,000 people globally have engaged with this project in one way or another in its many different shapes and forms.

No two stories are the same. Hearing these stories we cried, we laughed, we were enraged, we were heartened, and we found it important to share these stories with you unadorned. These are all unique stories of individuals and yet the emotions and experiences they reveal are universal; as recognisable to you and me as they are to the storyteller.

In 2020 *Daughters of Fortune* entered its legacy phase. I hope when you search online for "learning-disabled parents" the result you get will be different from mine five years ago. I hope the narrative of learning-disabled parents has become more rounded and truthful. Some of the poignant images in this book may even top Google image search results. There is always hope.

Joyce Nga Yu Lee
Artistic Director, Daughters of Fortune



A big world

D We've known each other for years. We met through football. As usual! We used to be in a mixed team. We knew each other but we weren't talkative. Then we met at a party six years ago, a birthday party, and then I had him on Facebook and we started speaking and I told him to come down to play football and he did.

G She used to kick chunks out of me!

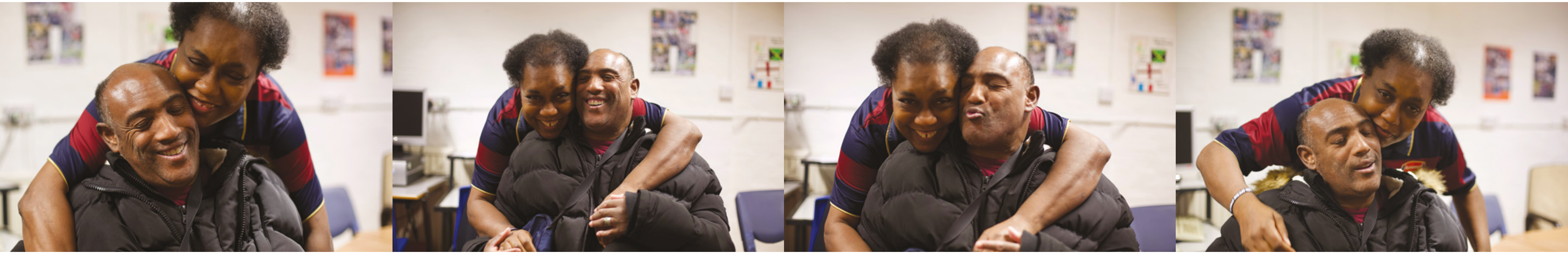
D And then we got married. Now we've got our own football team. Bluerays.

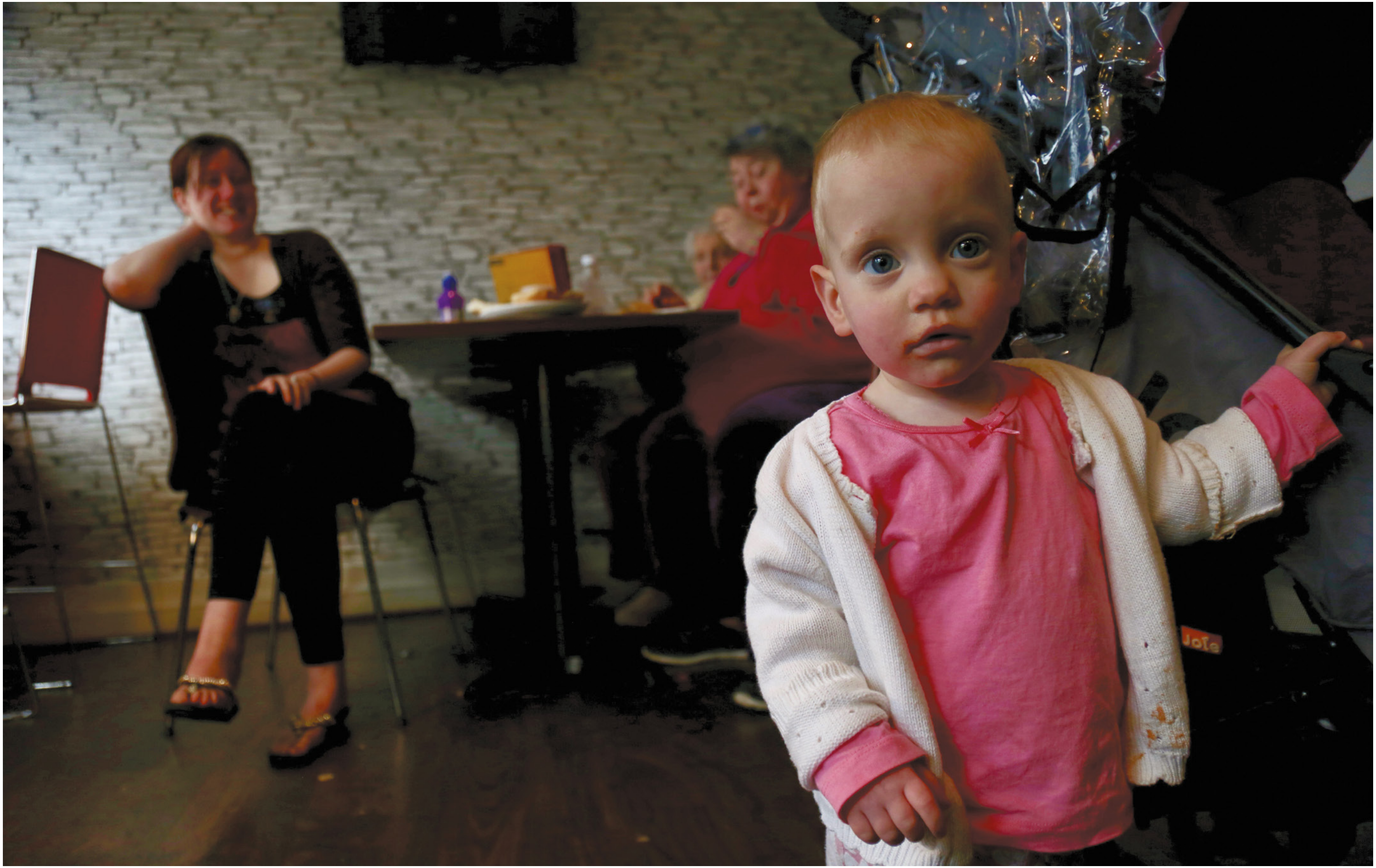
G They've done well.

D I've got a learning disability. I've got six kids, seven grandchildren. Four-step children. Three step-grandchildren – and one on the way.

G I've got four children, three grandchildren and one on the way, six stepchildren and seven step-grandchildren and a lot of people to care for. It's a big world; it's a big, big world.

D It is. It certainly is.




Joie

Just look at her now

When I was young I always wanted children, but the biggest problem for me was finding someone who would want me for me. I fell in love with my husband at first sight, which sounds very cheesy but is absolutely true! By then I'd already stopped looking for 'the package.' I took a leaf out of the Bible and looked with my heart not my eyes, and I saw him, and fell in love with him. I noticed something that other people hadn't seen.

When I told him I'd always wanted kids he was like, 'Well, we've not even been together that long yet'.

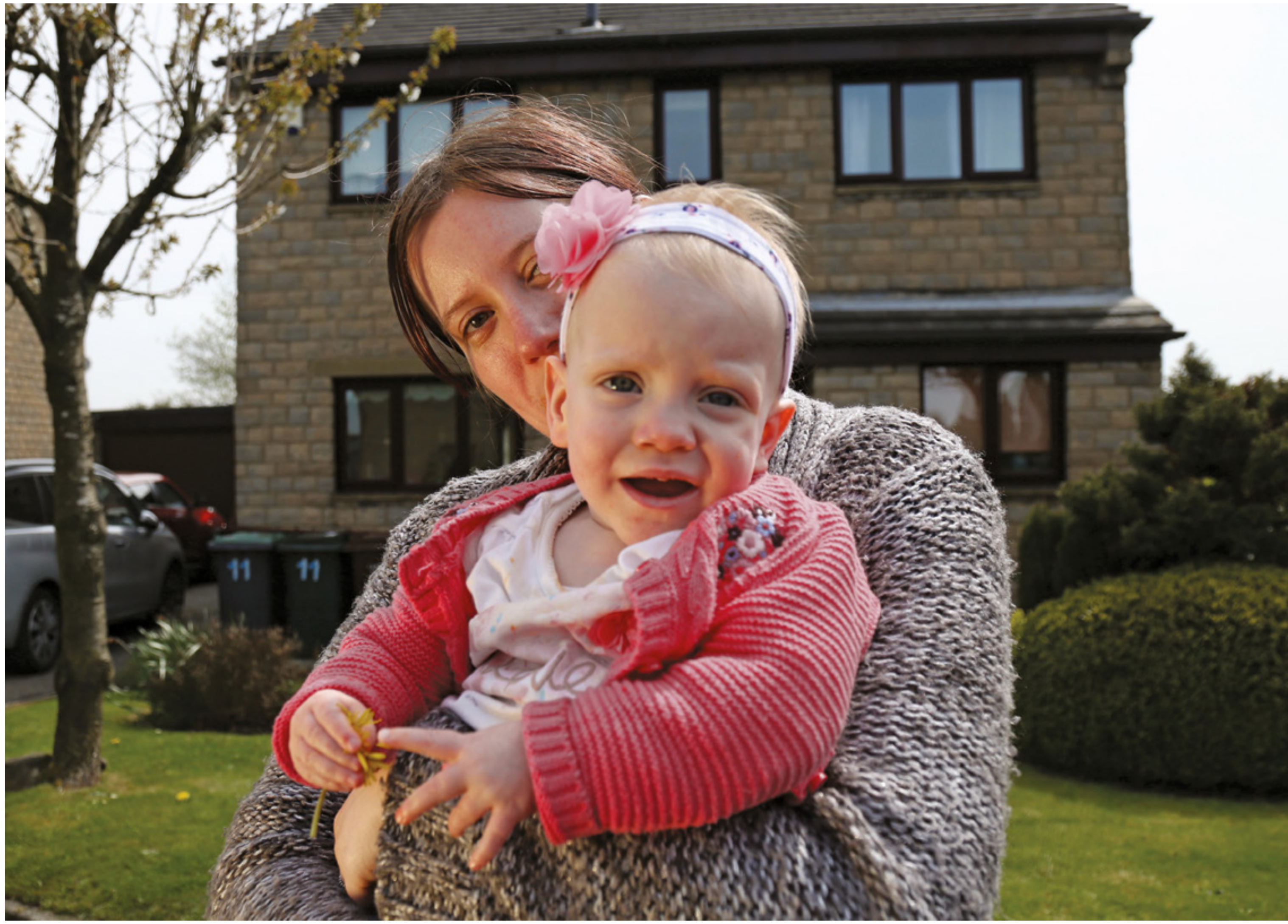
When we were chatting with the advocates about starting a family the statistics they told us were quite scary; something like one in ten Aspergers people were allowed to keep their baby. I was determined we'd be the one in ten! When I found out I was pregnant I was over the moon and he was like, 'f-word, I didn't actually think we'd get pregnant that quick!'

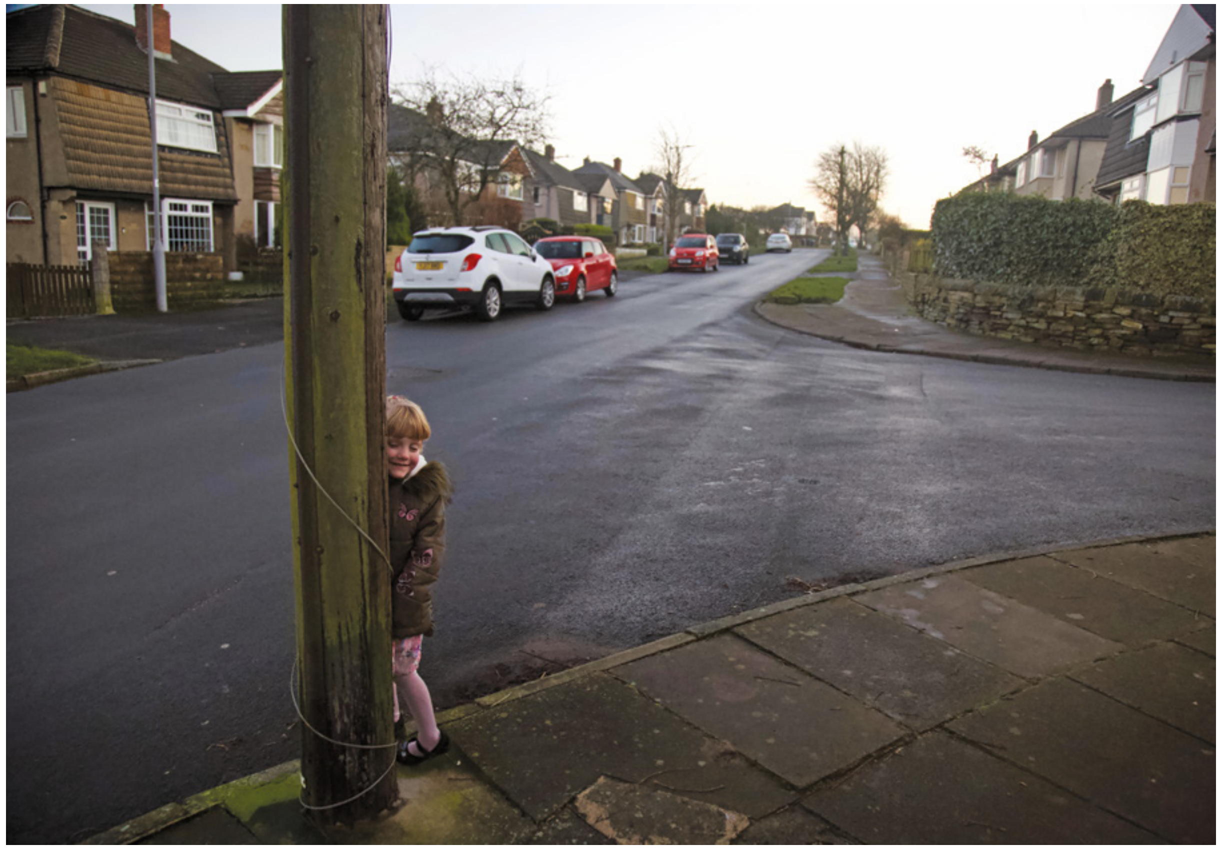
When my mum came round and I told her, she got up off our couch and gave me a massive hug. She did say she wasn't going to be a doting grandma but she's gone back on that!

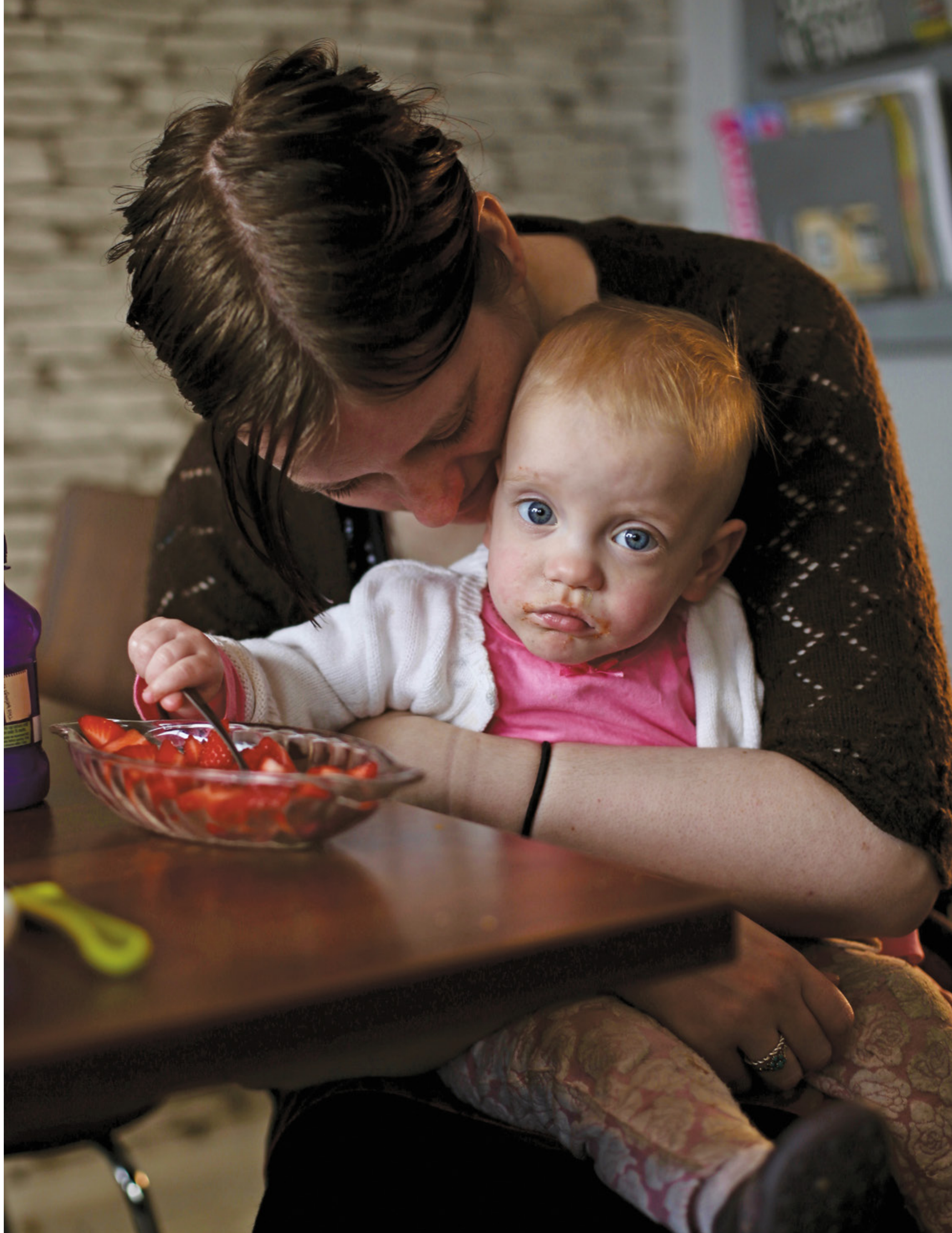
Our daughter was very prem; she looked like a skinned rabbit, in my husband's words. I wasn't allowed to hold her because she was so early and she was very ill in hospital for a long time.

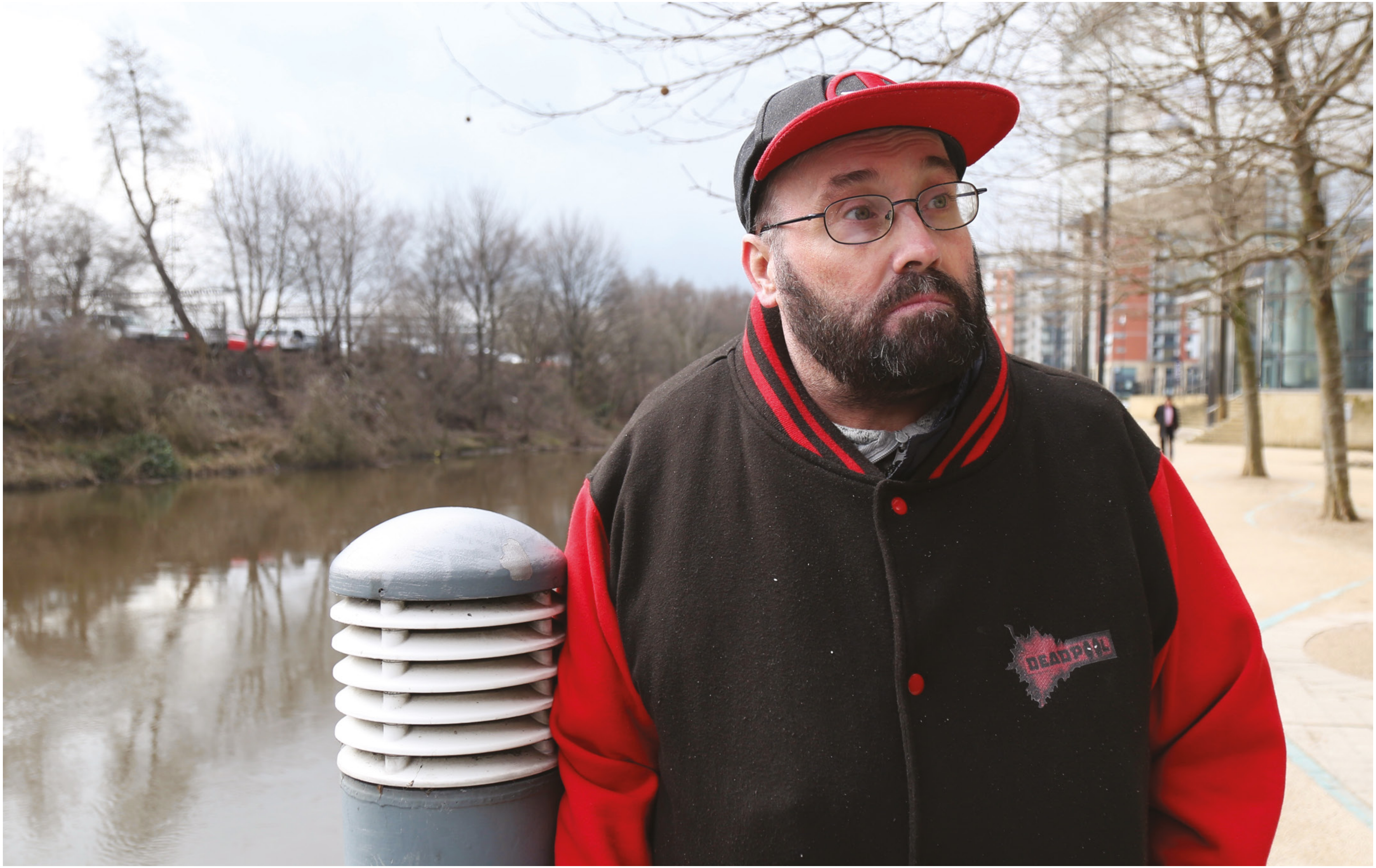
We were very strong as a couple during all this. The first three months after she came home she had feeding tubes so we had to be her nurses as well. The main thing is, she's doing so well. You wouldn't think she'd had all that trouble. Just look at her now!

“The first conversation I had with him about having children he was like, ‘Are you nuts? We’re not ready.’ But is anyone ever ready? And now we’ve got two children!”








DEADPOOL

“My grandson’s been adopted.”

“I offered to look after the baby.”

“Social Services didn’t take me seriously because I’ve got a learning disability.”

When my girlfriend found out she was pregnant, it was terrifying. I was happy but scared; a lot of mixed feelings. I told my dad and he said, ‘Oh, another failure. You won’t keep it.’

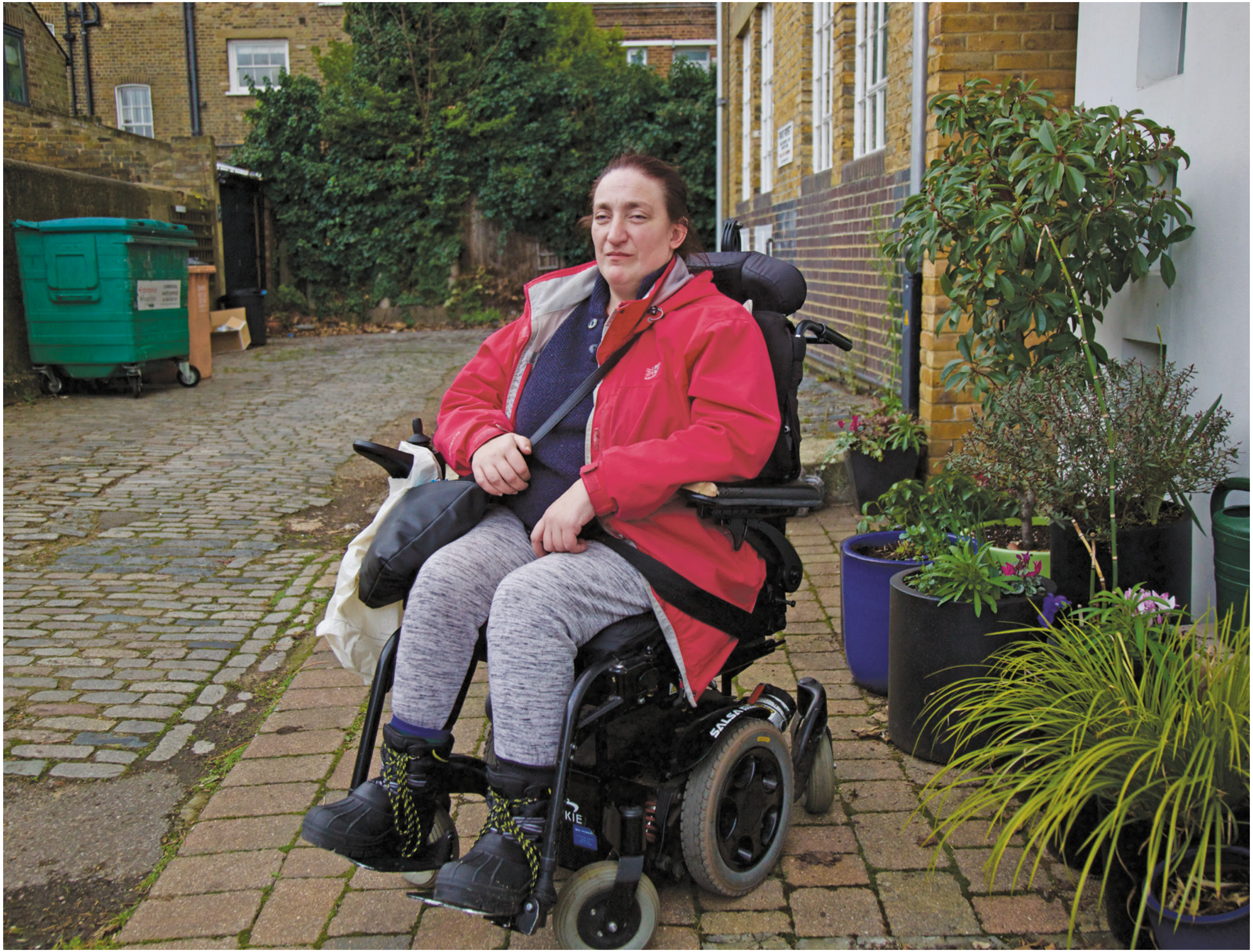
My mum supported me. She was a fantastic mum. I was determined to do the right thing with my kids. I didn’t want to be like my dad, I wanted to be the opposite.

We kept the news in the family. I was scared of social workers. People called them child-snatchers.

When she went into labour I went into hospital with her. I felt part of it all. When I saw his head coming out I felt so emotional, happy and proud. Honoured. I was crying. I was 19; I had to grow up. All my friends were going out to the pub, playing football, being teenagers. I had to step up and be a dad.

I wanted to do my part looking after my son. My first experience was very scary. It was like holding glass, I didn’t want to drop him! I had to make sure I was holding his head up when I was bathing him; clean him down with wipes and sponges. My mum showed me how to do it. When I got more confident I started to change nappies and bath him and feed him myself. I got better bit by bit. I was very determined. It was a good time. It felt like a proper family.

Sometimes I think about what my dad said, ‘You’ll never work, you’ll never live on your own, you’ll never have kids.’ He was wrong about everything. I work, I live independently, I have kids – and now I have grandchildren.



“Everyone stared at me thinking, ‘Oh my God, she’s pregnant and she’s coming to school.’”

I loved being pregnant. You know when you… when you’re not worried about anything, you focus on the one thing that is there, that’s growing inside you, every minute of every day.

I had a son. I felt so happy! So calm, I didn’t feel stressed out. I felt, ‘Wow. I’m a mum.’

The first time being alone with him, I remember everything! Because I was worried I would drop him. I didn’t. I fed him, I took him out, clothed him, changed him, everything, I loved it. My mum was a good help.

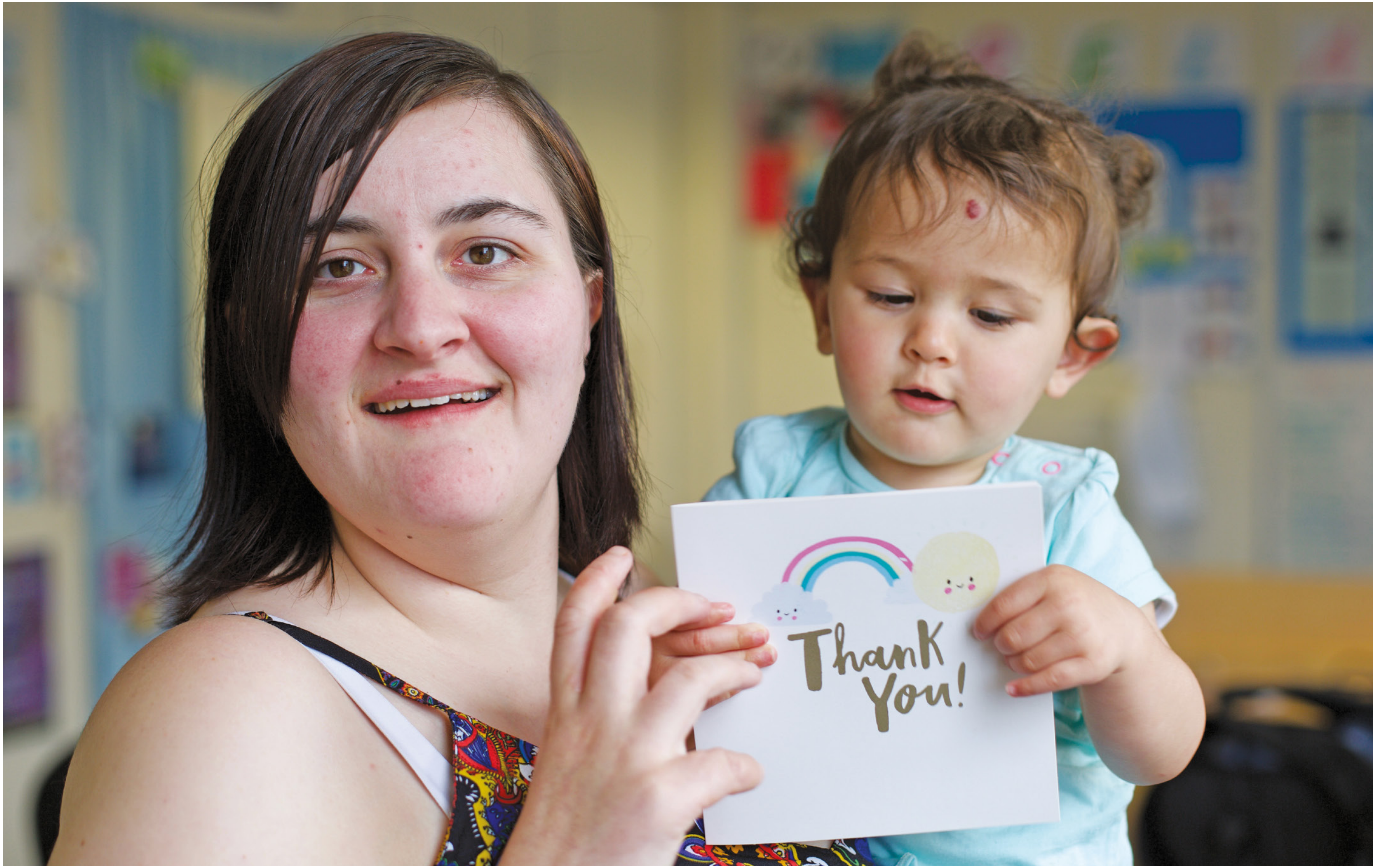
My daughter was born in 2006. It was at my mum’s house. My sister had to deliver the baby! She was only 13 at the time. She done really well actually.

My third child was born in 2008. Yet again I loved it. The only thing I didn’t like was breastfeeding. I breastfed the other two; it was very painful but I did it! It meant a lot. I had support from my mum, my sister, even my dad’s come round. He’s a good granddad now.

I was happy, and I’m still happy. There are things though that do bring me down, and do make me feel… rubbish.

All three children have Global Development Delay. I had social workers coming in and out of my home. Social put us on Child Protection so I did everything in my power to keep the kids. When we came off Child Protection I was over the moon. We’ve not gone on Child Protection since, and that’s the way I want it.

What’s the best thing about being a mum? Having the kids. Did I ever feel I was going to lose them? Every single day. Every single second with them counts.


Thank You!

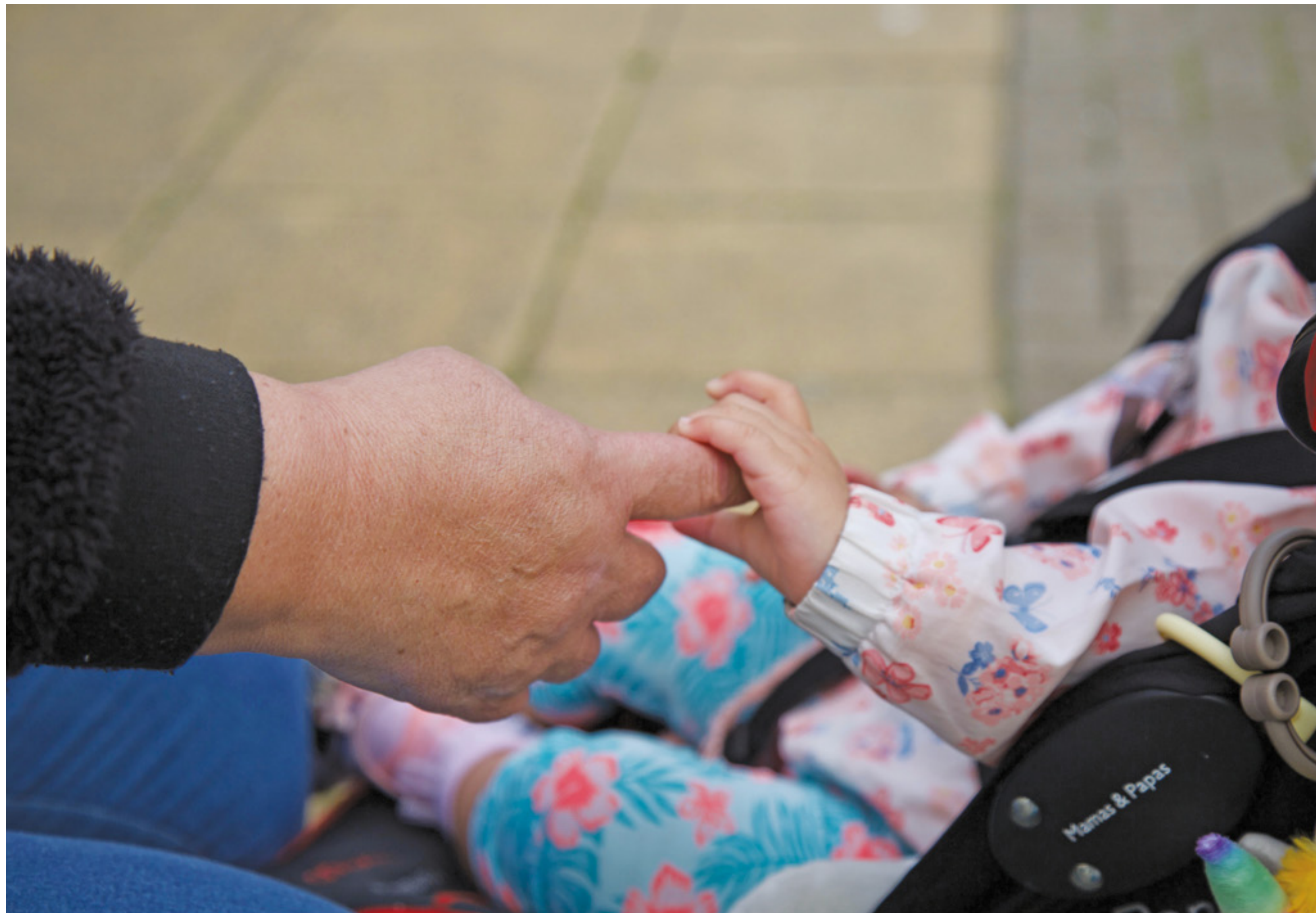
I lived in Dewsbury with my ex-husband but we're not together anymore so I moved back to Halifax to be near my mum; she's always been my main support. I never had any involvement with Social Services.

I was 19 going on 20 when I met my ex. I thought he was a really, really nice person. He asked me if I wanted to marry him one day when he was helping me learn to swim. He just said, 'Do you want to get married?' And I said, 'Yes, but you'll have to ask my mum's permission first.' I hid in my bedroom when he asked her. I'd known him two or three months then. I knew I wanted to be with him.

I had two miscarriages before I had my daughter. When we went for my 12-week scan I literally put my hands under me with my fingers crossed and I was thinking, 'Please be a heartbeat, please be a heartbeat.' And there was – and she was kind of waving at us.

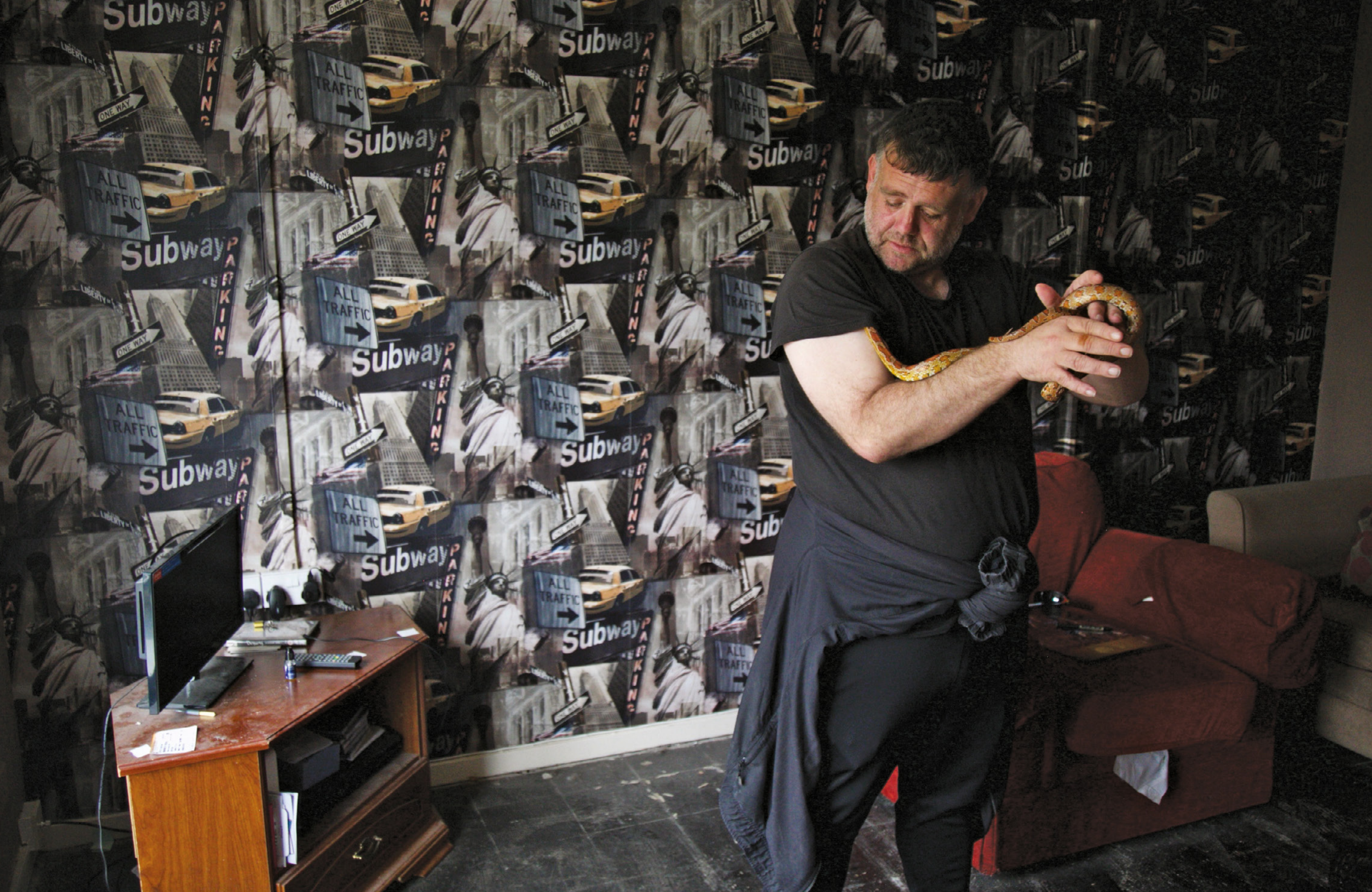
The good things about being a mum? Watching her grow up, buying her clothes and shoes, teaching her to walk and talk, to feed herself, taking her to parks. And we go swimming. I'm taking her to Blackpool for the first time next weekend. I go to my mum's every week for Sunday dinner. She loves it, especially the Yorkshire puddings. I call her my Yorkshire pudding baby. In a way I do spoil her 'cause she's so precious to me.

Being a mum with a learning disability is difficult but there is support out there to help you. Even if it's not professional support, you've still got your family. I've had lots of support.



Able

When I was 15 or 16
My mum said,
'You might not be able
To have children;
You might not be able
To carry them full-term.'
I wanted to be able
to have children;
I wanted to be able
to carry full-term.
I lost two children
To miscarriage;
I carried my daughter to full-term,
And no one has ever said
'You are not able
To be a good mum.'


Subway
PARKING
ALL TRAFFIC
ONE WAY

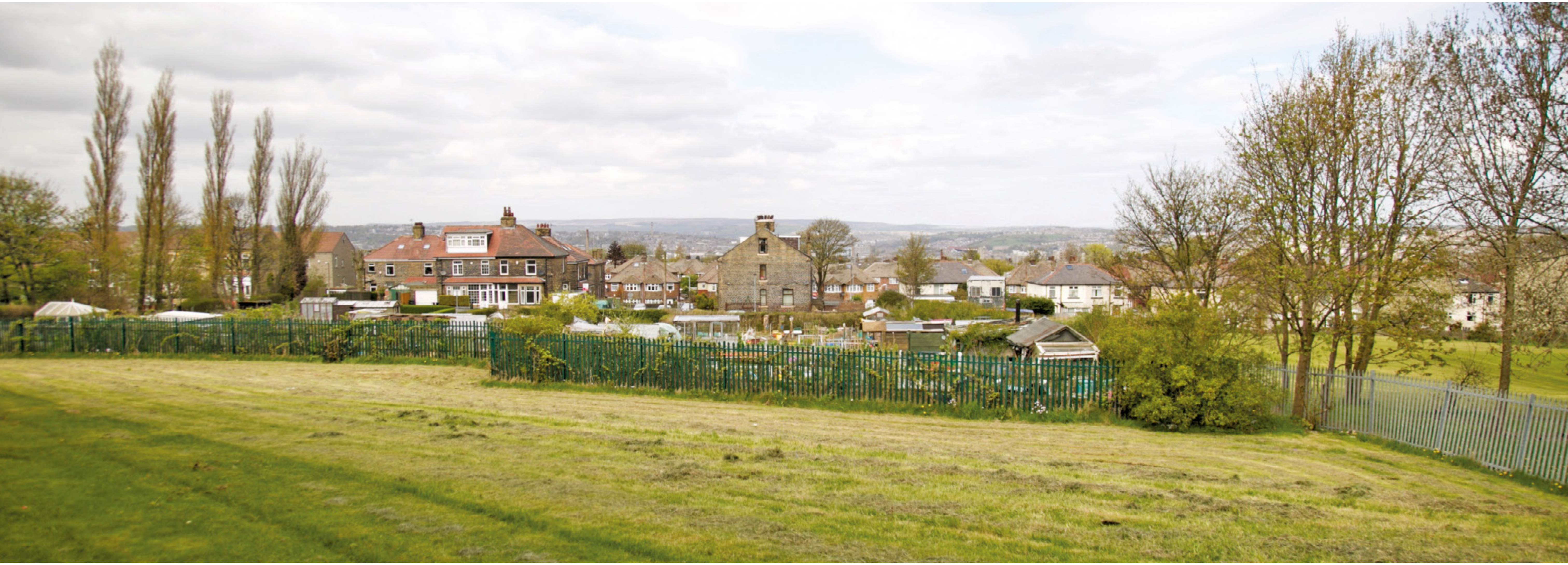
At school no one talked to me about my body changing or about sex. They thought learning-disabled people didn't have sex. It was my mum and dad that taught me what was right and wrong; how to treat your partner and to give them respect.

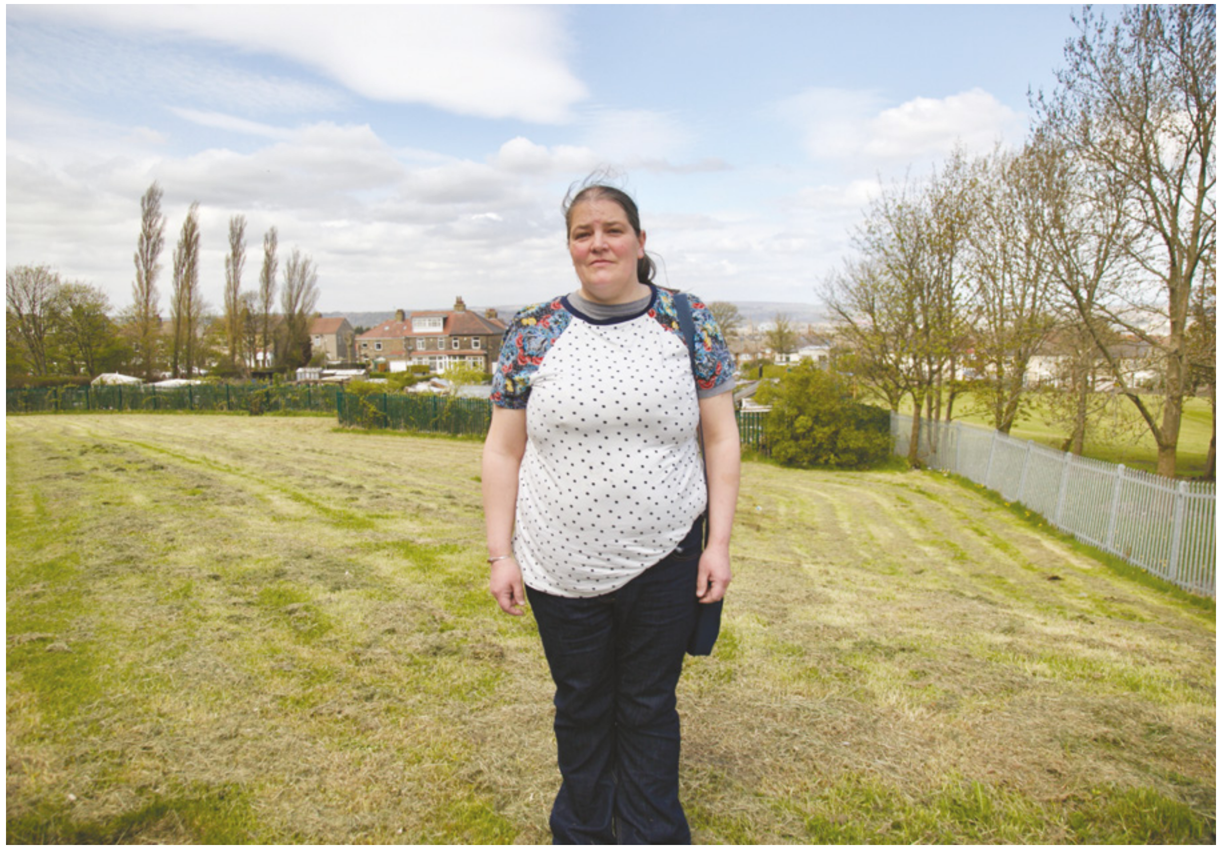
I didn't want to rush into settling down and having kids. I wanted to live my life first.
I wanted to go out, go out with my friends, go out into the world. I had full-time jobs, part-time jobs; I did catering and cooking. I wanted to live my life.

I got into a relationship and we were together for two years. She had a learning disability too. We sat down and we talked about having children. At the time, no, I didn't want children. At first it was going well but the days and months went by she was pushing me so much to have kids. I wanted to wait. She wanted kids. Then we split up.

Not long after she came looking for me to let me know she was pregnant. I was a bit shocked at first. When the baby was born I was over the moon. I'm happy now
because I spend a bit of time with him. I like to walk him around and take him out and play with him. Sometimes I go over and I put him to bed.

On Fathers' Day she sent me a framed photo of him saying 'Best Dad in the World'. It's in my bedroom on the top of my snake tank and when I wake up I can see him. My ex has a lot of support from her mum and her dad; they're there for her day and night. There wasn't a social worker involved at all.





“He was a similar age and he wasn’t learning-disabled. It was romantic and I was happy.”

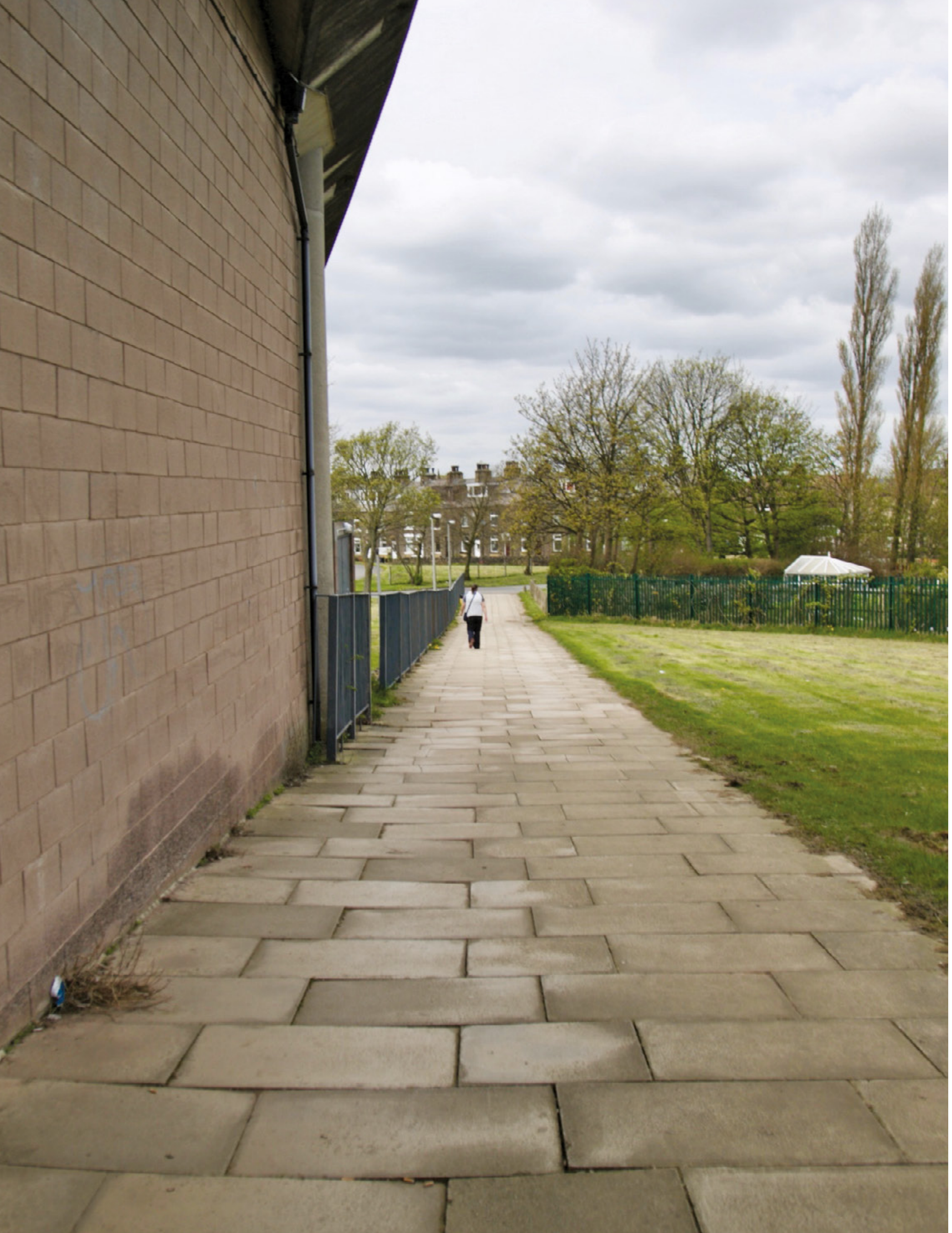
I went to the doctor’s thinking I wasn’t well and he told me I was pregnant. I was shocked because I wanted to wait until I was older. I was 23 and I was working at the swimming pool. When I told Dan he was concerned because we didn’t have our own place to live.

I finished work and looked after the baby. My mum and my family helped me a lot. Tom was diagnosed with a learning disability at 3. I was happy but a bit sad because I wanted him to have a normal life and I know it’s not like that with a learning disability.

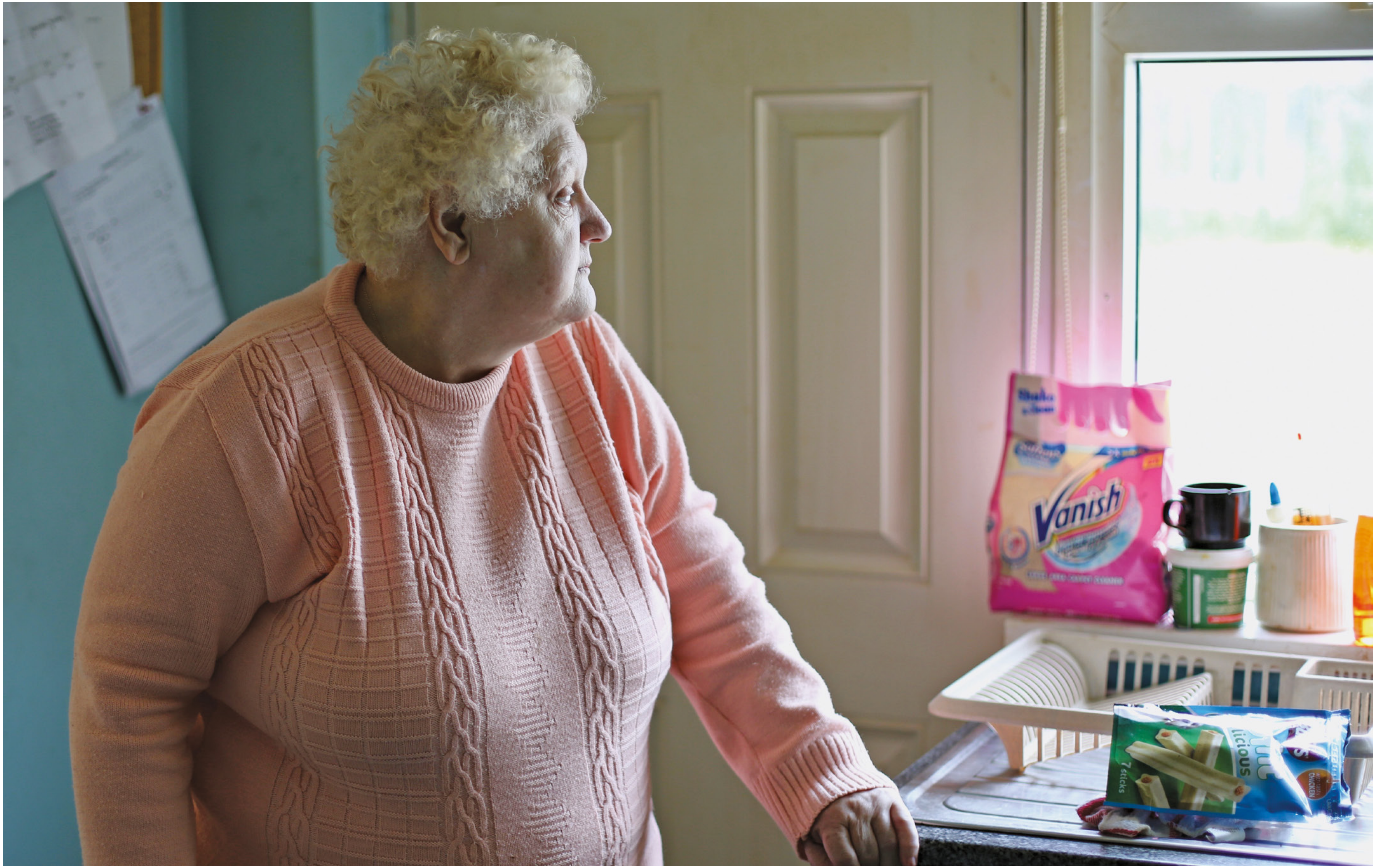
Tom’s brother Lewis was born when I was 25. He’s 17 now and lives with me. We’ve got a nice place of our own. I was pleased to be pregnant the second time. We planned the pregnancy. Lewis was also diagnosed with a learning disability. When they were both diagnosed with a learning disability Dan didn’t want to know. He left.
It took a long time to get any help with Tom. He’s 20 now. He’s in a home where he’s looked after and he’s happier and safer and he can’t run off and he can’t hurt anybody. I still go and see him.

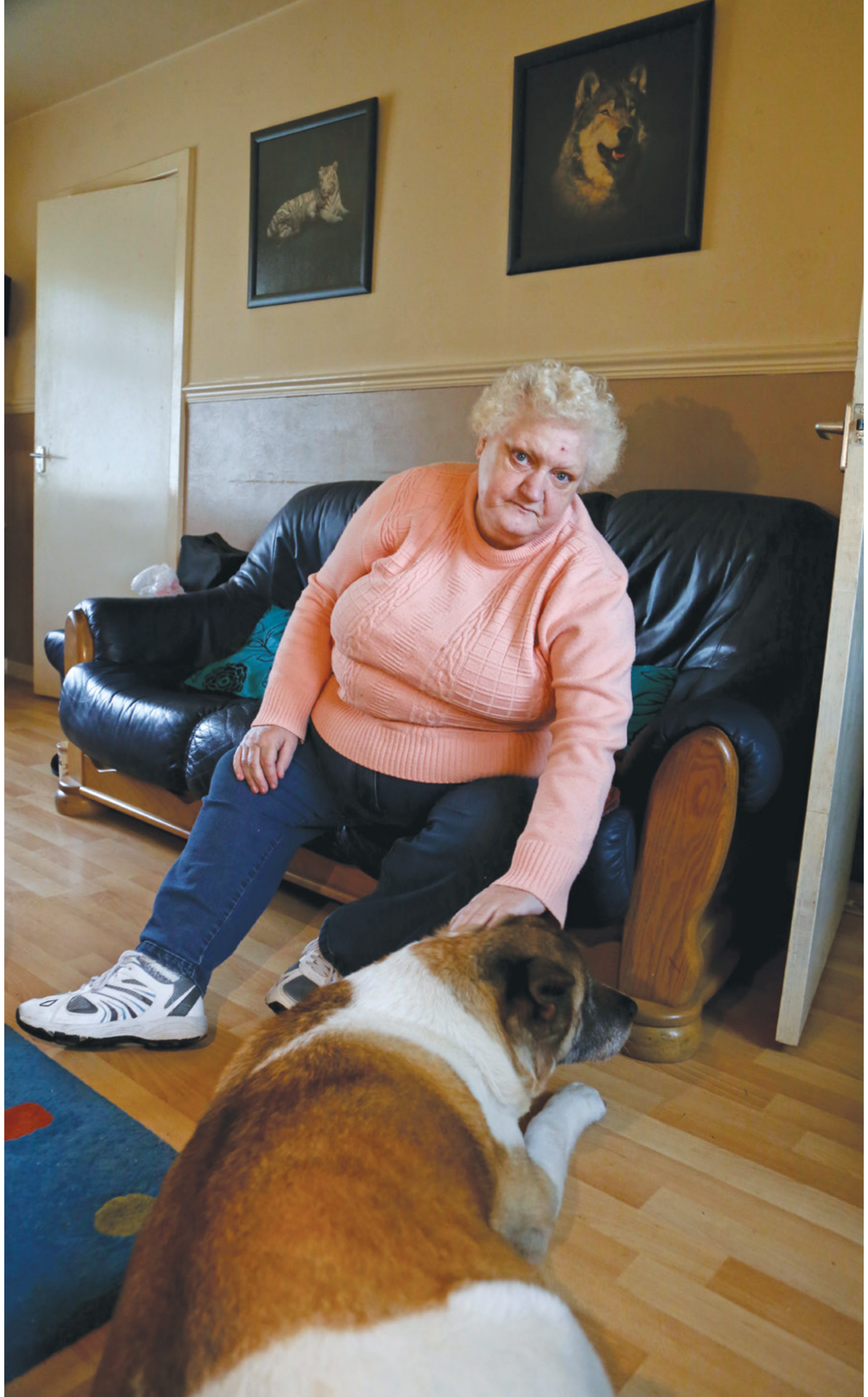
The best thing about being a parent is spending time together; going for walks, going to the park, going to the pictures, going on holiday to Blackpool. It’s hard work but the most important thing is just being there, spending quality time with your kids, and loving them and taking care of them.

Don’t listen to people when they say you can’t do things because you’ve got a learning disability. You can do lots of things, including being a good mum.



“We didn’t talk about having children. We didn’t use contraception. So it was a mistake. I wanted children but we didn’t talk about it.”


Vanish



“They weren’t talking to me, they were talking about me. The advocate said, ‘There’s a person in the room who you should be talking to.’”

Being a learning-disabled person myself made it hard. It was very hard with Jessie because she was a child who never slept. I was up every night with her. I never got any sleep. She wanted to be up, up all the time.

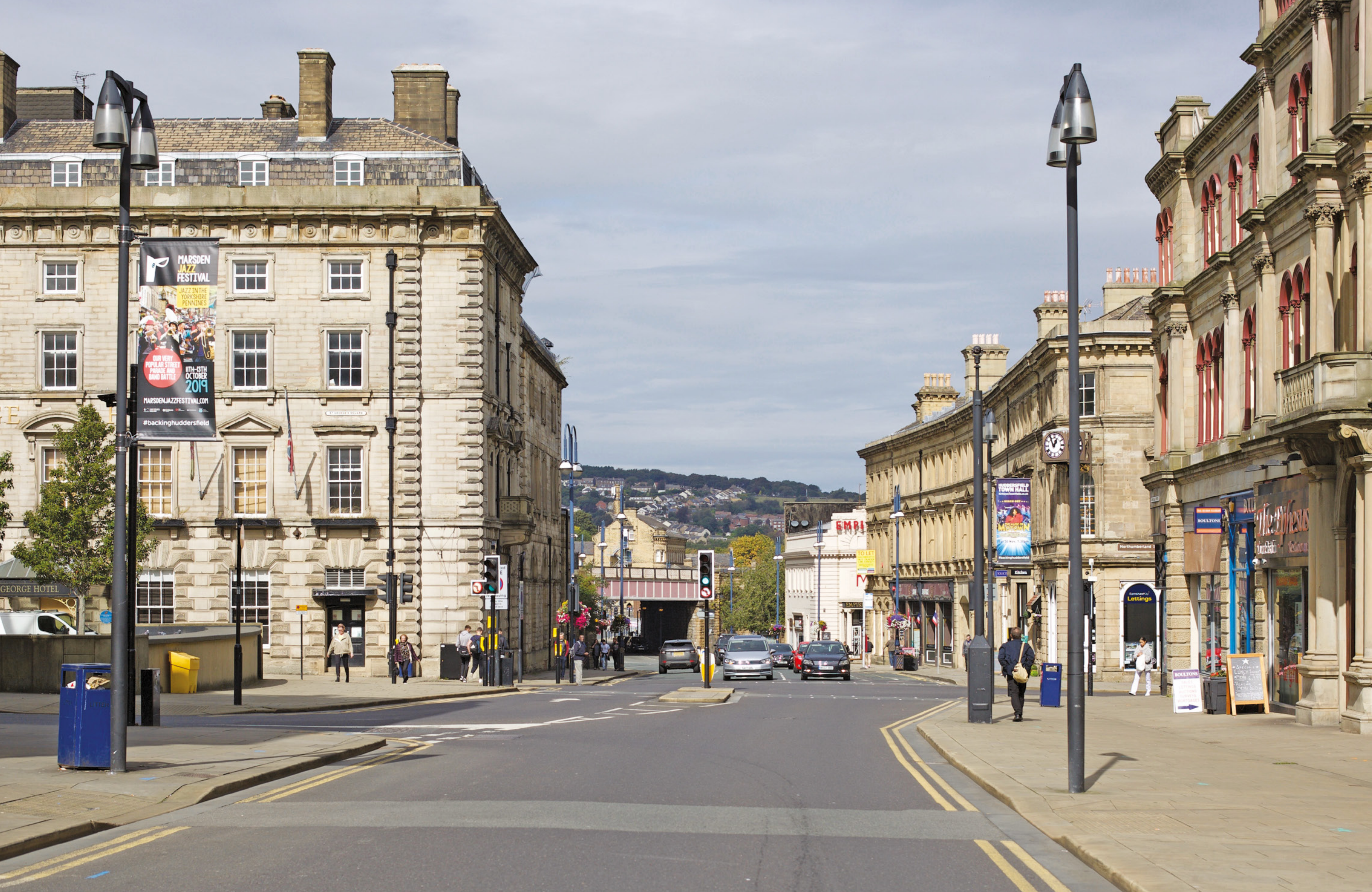
But you’ve got to cope. I got respite care. They took her for a week. My mum helped out; if it wasn’t for my mum I don’t know what I would’ve done.

Money was always hard too. For example, with the school uniform, she could’ve had hand me downs, but she was so small for her age, I had to buy everything new. I saved up for her uniform. My mum helped me buy it but then I saved up and paid her back.

I used to make sure bills were paid and everything, food and all, then anything left over I gave to my mum to save for a holiday. We used to go to Torquay. When I was booking I always had to explain about Jessie, that she was special needs. I worried she might break something – we wouldn’t’ve been able to pay to replace it. But she was really good on holiday. And I did get a rest. My mum used to take her to bed and sit with her so that I could come downstairs. And the staff were really good with her.

Anybody who’s got a disabled child and is disabled themselves, I feel sorry for them. Because some of them don’t get any help at all. They don’t know where to get help. I say, don’t try to do it on your own. It’s too hard. Tell somebody. Tell somebody and get help.

“The advocate and the solicitor said, ‘Why should Jessie be put into care when you’re a good mother?’”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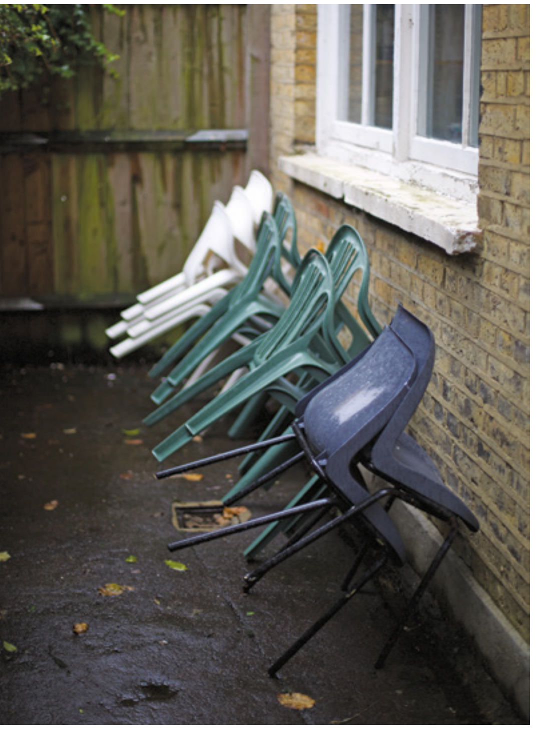


Charlotte has a disability and it was really scary at first bringing her home. I thought, ‘What happens? What do I do?’ but it just came to me. I knew what to do and since then I just got on with things.

It’s been great being a mum really, looking after her. I’ve sacrificed a few things for her. You know, that’s what motherhood’s got to be about really, sacrificing to have a lovely girl which she has grown up to be now. She’s seventeen.

She’s at a special school and a bit delayed with things like walking, talking, reading. But now she can read, write and spell. She does the computer. She’s typed up her stories. She can read big thick books. She’s nearly grown up. She’s got to be independent; dress herself, which she does do. Do her personal care, and do other things what she should be doing now she’s a teenager.

She’s moving on to the transitions team. Adult social care. She stays in the special school for two more years and then we’ll have to think about which college she goes to. She wants to go to college. She’s told me that. We had a Children in Need meeting to discuss the future, college, and whether she might move out to independent living. Her social worker said she won’t cope in independent living ‘cause she’s very vulnerable. She talks to people she doesn’t know.

I’m her mum. I do her personal care, give her a bath and things like that. I think Charlotte should stay with me.


TOP BRANDS
CRAFT DRAUGHT
BOTTLES CANS
REAL ALES
HELLMANN'S
REAL
SARSON'S
Malt

> “The snow was up to here. I says to foster mam, ‘Can he come for his dinner?’ and she says yes. I knew it would be alright ‘cause I could keep him occupied with clearing the snow and making snowmen together.”

I had an easy pregnancy, it was just the back ache. The midwife knew I went to special school. They came to the house, I was assessed and I was doing everything right. He was premature and he was about eighteen months or two years behind. I never ever neglected him. He was always clean. I took him for all his injections. When he was two I took him to the paediatrician who said he had learning difficulties.

All the problems started when he was three. He used to bang his head and hoy things a lot. He used to bite and when he got to five or six it was scratching. I used to do the Lego with him, play shops, bubbles, painting, play dough, jigsaws. I got the paddling pool out.

When he got older, I got the fences in the back garden built six foot ‘cause he would try and climb over. I liked to take him out, but we had to take him to quiet places. We took him to the coast and Hexham Park and he was watched all the time.

I had a lot of help from my mam. They wanted to take him away at six, but my mam says, ‘No’. Then he burnt my house down. The fire officer said there should have been somebody there, but my mam was too ill. She only lived eight months after. I was upset at first when he was fostered but his foster mam only lived three bus stops away. She was very good.

He’s in supported living now. We go out once a fortnight. We go to Wetherspoons. We go to bowls. We go to the shows. I’ve never walked away from him. I’ve been there all the time.


ONE
SMALL
TEP

D I helped with the birth. I was there when the waters came out and the lot. I cut the cord.

M He was there for the cursing!

D And the swearing. I was there three times a day at the hospital. Day, morning and night.

M I knew they were going to take the baby away. I had a feeling. I wanted to bond with the bairn. I started breast-feeding and they stopped me.

D We ended up with a meeting at the hospital. And I says, 'Oh, this is it.' It had all been set up without us knowing and she had to actually hand the baby over to the foster parents. We didn't get a chance to take him home or nowt.

M It was really bad. I was in tears when it happened. I can't understand why they had to do it…

D I tried not to feel much emotion because if I did I would've upset Michelle even more and she might have thought she was a failure. She's no failure.

M I did feel like a failure.

D But you weren't no failure, Michelle. You're no failure.

M I think it was because I've got learning difficulties, and the problems that Dave's got as well.

D Even our solicitor said, 'Don't take it any further. You've got no chance. Just surrender.' We fought to hang on to the bairn in the court and I got to question their solicitor… Ryan was fostered at first and then adopted. Social Services pay these foster parents to look after our own kid. That money could go towards us being better parents. With that money and help from the professionals we could have looked after him.

M That's true.

D But social services says there's no money for us.

M As long as we got the bairn I would have done anything they wanted. Anything.

D The thing is, they don't know us as people.

M They don't.

D They don't know me and Michelle.

M They didn't even sit down and talk to us properly. They don't know us. Other than going through thirty years of your past and you have to tell them what happened years ago and it traumatises you again.

D My problems started when I was about 13 – I started hearing these voices. I had schizophrenia which wasn't diagnosed at the time. My father used to abuse me and I couldn't keep myself up to scratch with the world. I took drugs so that I could forget about the voices. It took me years to settle myself.

M It was really humiliating going over it; bringing back so many bad memories.

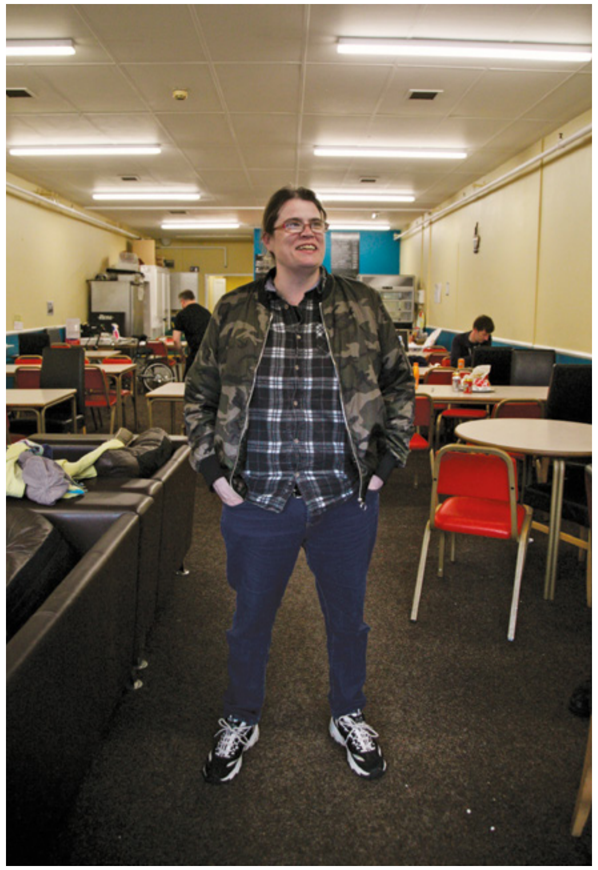
D I said it's the present and future, not the bloody past that matters. The past is buried as far as I'm concerned.

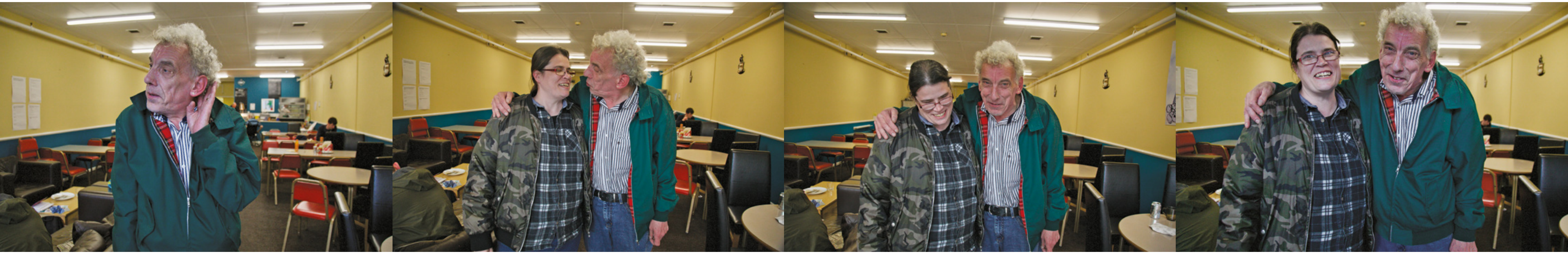
M They are just looking for faults all the time. That's what was doing my head in. You do one thing wrong and it gets written down in your report.

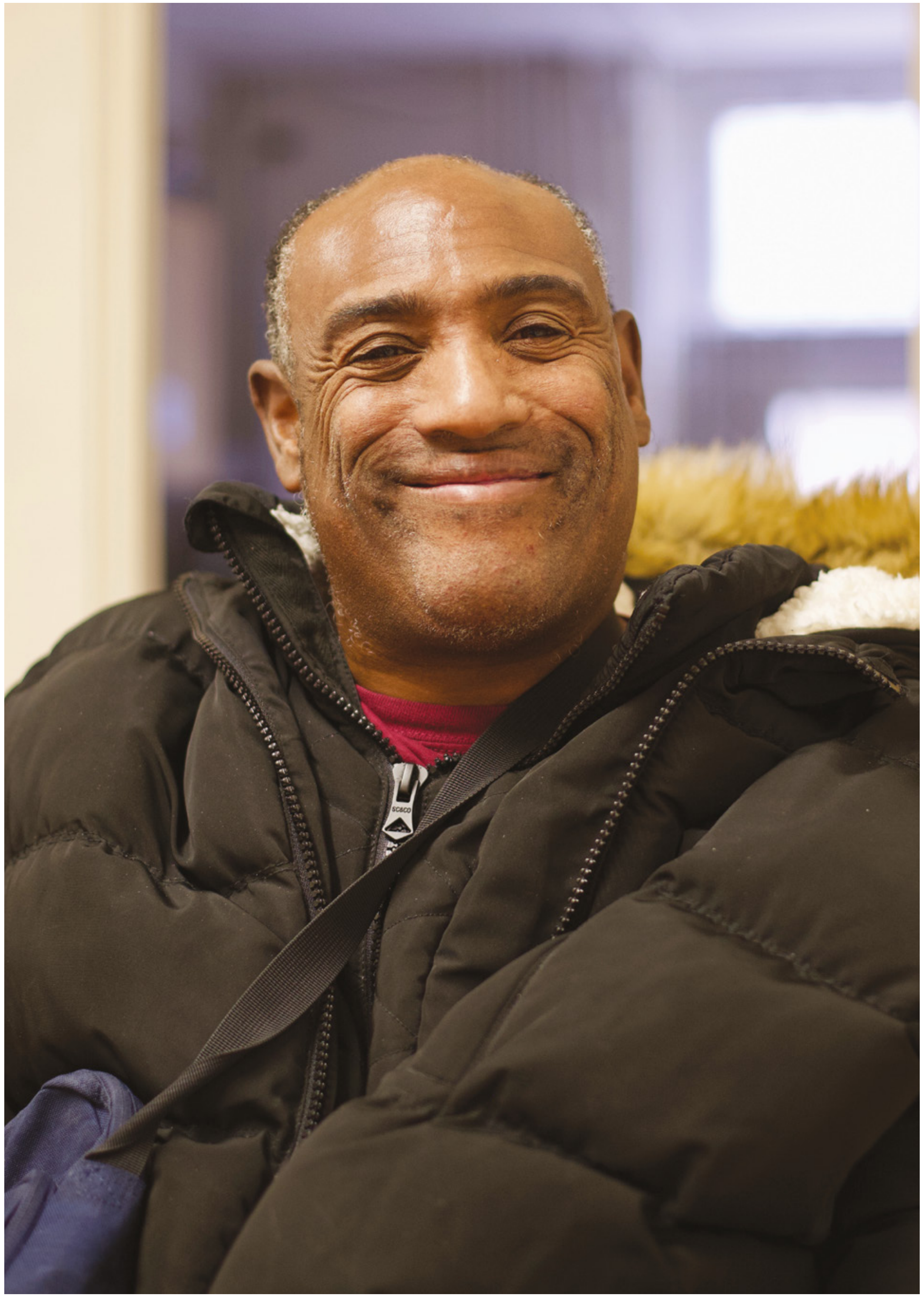
D The truth is you're a great lass. I love you very much. She's a hell of a lass, man.

M Try telling the social services that.

D Don't worry about that, you're a hell of a lass! I'd die for you. And I'd still come back and haunt you!







"A learning disability is not a loving disability."

I was 21 when I had my first child. I was over the moon. I was very, very proud. I have four children. The youngest is sixteen. I don't see a lot of them; things got messy.

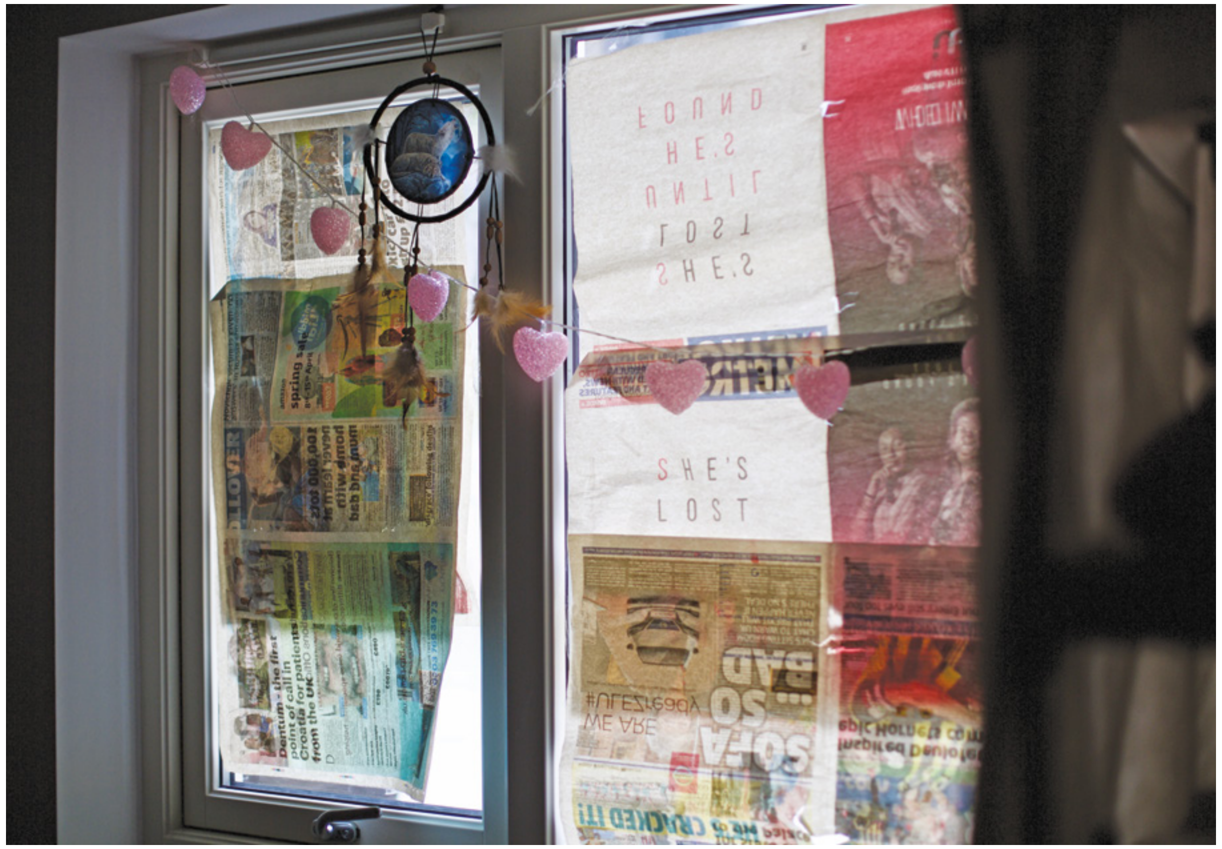
I was on medicine and I lost my temper and lashed out. I took myself to the police, handed the keys down – and that was it. It got me depressed to the point where I wanted to end it all. I'm not proud of it, but at the end of the day, I've just got to see it as a learning curve, a very, very… hard learning curve.

From a father's perspective, the system is too snaky. There's fathers with a learning disability who will tell you that they've been kicked to the kerb. Then social workers say, 'the fathers don't want to know'.

Now I speak up for people with learning difficulties, disabilities and medical conditions. I go up and down the country speaking. I do conferences and seminars and I tell it like it is.

It's alright for able-bodied people to stand up and make a lot of noise, but when somebody like me stands up they're classed as a troublemaker. You want me to be all lovey-dovey but I'm not telling you what you want to hear. I'm telling the truth.

What's the point of telling people my story? Is it going to make any difference? I want to hear what people are doing, not what they're saying.


SHE'S
LOST

January
Everything went wrong when I met Robert. My social worker told me he was dangerous. I had to finish with him to protect my kids. That's why my two kids are in care; his police record.

When they told me my baby was going to get removed, when I'd just given birth, it was really heart-breaking. I was crying all the time. I didn't want the baby to go. My heart just split. I said, 'You can't take my baby. You really can't.' But they said, 'We're just doing our job.' No one asked me about my feelings or what I wanted. They didn't care. They just thought about the baby.

My social worker came home with me. But I had thoughts in my head saying, 'What's the point of carrying on now?' But everyone says I can't do that. I've got to fight, haven't I? At the minute I'm trying to fight to get my kids back.

November
My final court appearance was in April. I read my statement saying why I want my children back. The judge said my kids were going to get adopted. That was supposed to take nine to 12 months but they got adopted four months later. I told them I wasn't with Robert anymore but they worried I might meet someone else the same – but why would I do that?

Now I want to help young people like me. I want to give awareness; how quick they can get beaten down, how having a relationship can be dangerous. When I met someone I didn't know anything about them. I rushed into it. You've got to get to know someone first, know about their background; if they're safe. That's what I've learnt. Yeah, that's what I've learned.

I'm not doing that no more

I kept letting people into my life,
And giving them money.
I thought they were friends,
Didn't know they were just takers.
But now I have to think about myself,
Pay my food, my bills, my rent.
I've learnt from my mistakes,
I'm not doing that no more.

My Dad was violent to my Mum,
Now he wants an oven, wants his shopping done,
In the past, every time, I've come running,
Though he don't help me when I'm down.
But now I've grown up, I've told him straight.
I'm not doing that no more.

The man I called my boyfriend, the father of my child,
Wouldn't let me go out, wouldn't let me have my phone,
Wouldn't let me see my sister, kept me frightened at home.
Back then I didn't listen when people told me, 'That's not right.'
But now I've grown up, I've put my foot down,
I've learnt from my mistakes, and I'm telling you straight.
I'm not doing that no more.
No way. I'm not doing that no more.
And please remind me if I forget,
I'm not doing that no more.

> **“Social worker was going wherever I go, checking me. I had to have solicitor again; tell them I don’t need child protection. We won the case. I was free. I was trusted to be a mum.”**

When I was young I was good at picking things up. When I was fourteen I got poorly and afterwards I am diagnosed with a learning disability. I can’t read or write or spell very well.

My ex-husband came to meet me in Kenya. Then I came here. It was a forced marriage. I didn’t like my husband but I love my children. I have four children.

My first child was premature. Really tiny – only 4lb – and she had jaundice. She was so tiny it was hard to pick her up. She was in an incubator. I never thought it was going to be like that. The shock of all those things happening to me, it turned my life upside down.

I had a wonderful midwife. She always helped me how to care and how to feed and if I had any problem I could talk to her. My ex-husband treated me like dirt; like I was worthless. He wouldn’t spend money on me or the children. He bought food but I had to sort clothes for my children. Wouldn’t give me bus fares. He never took us on holiday. I did find it hard and the suffering for my children. Then I found a very wonderful lady – she was a Pakistani lady – I started helping her to do the playgroup where she was working and she would give money to me and she would help me. She helped me find a cleaning job, she helped me find work as a dinner lady so I could give lots of things to my children.

I was earning money but I never told my husband about it. I couldn’t cope so I broke up with him. It’s been nearly 18 years since the broken marriage.

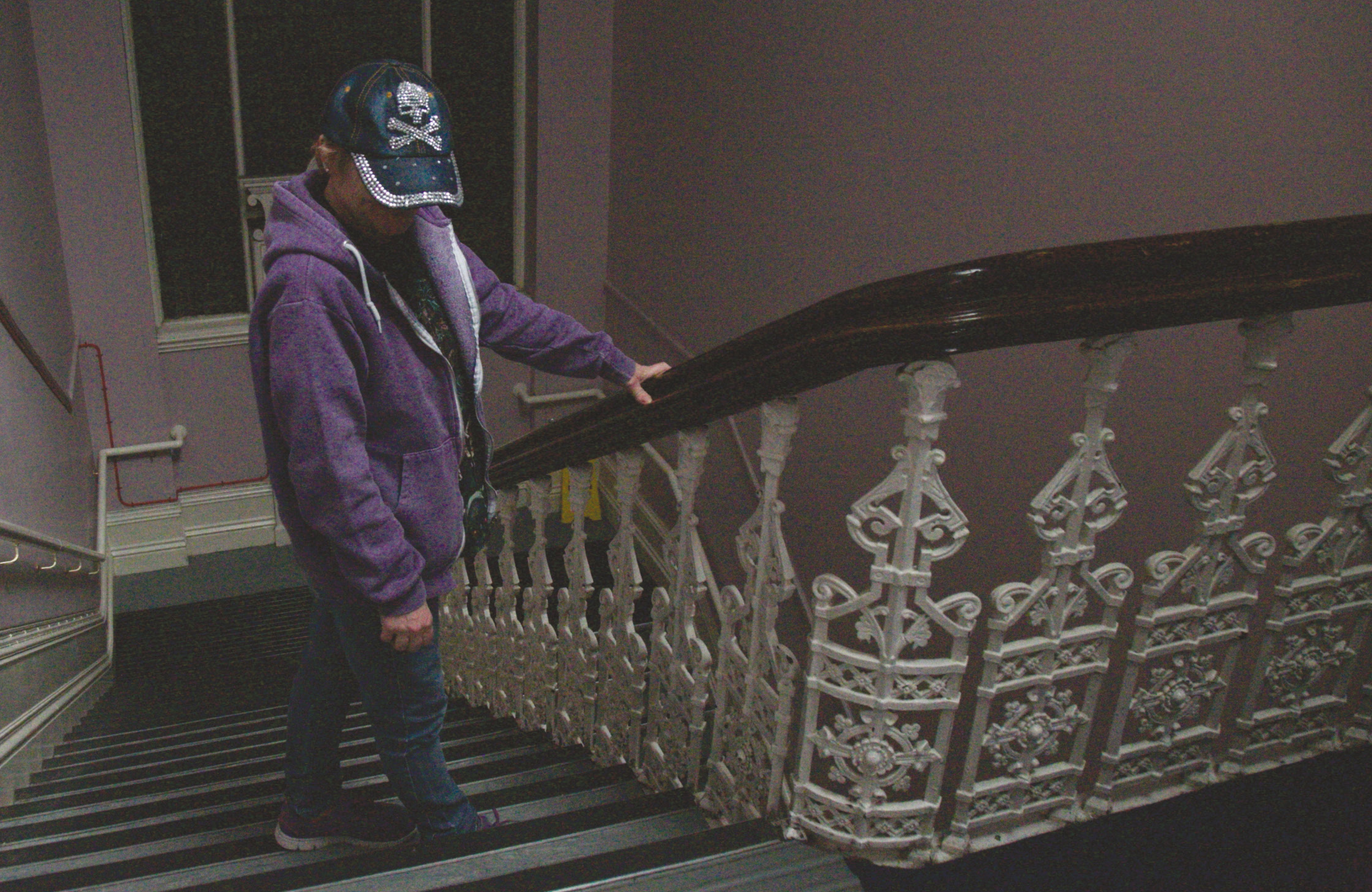
In My Culture

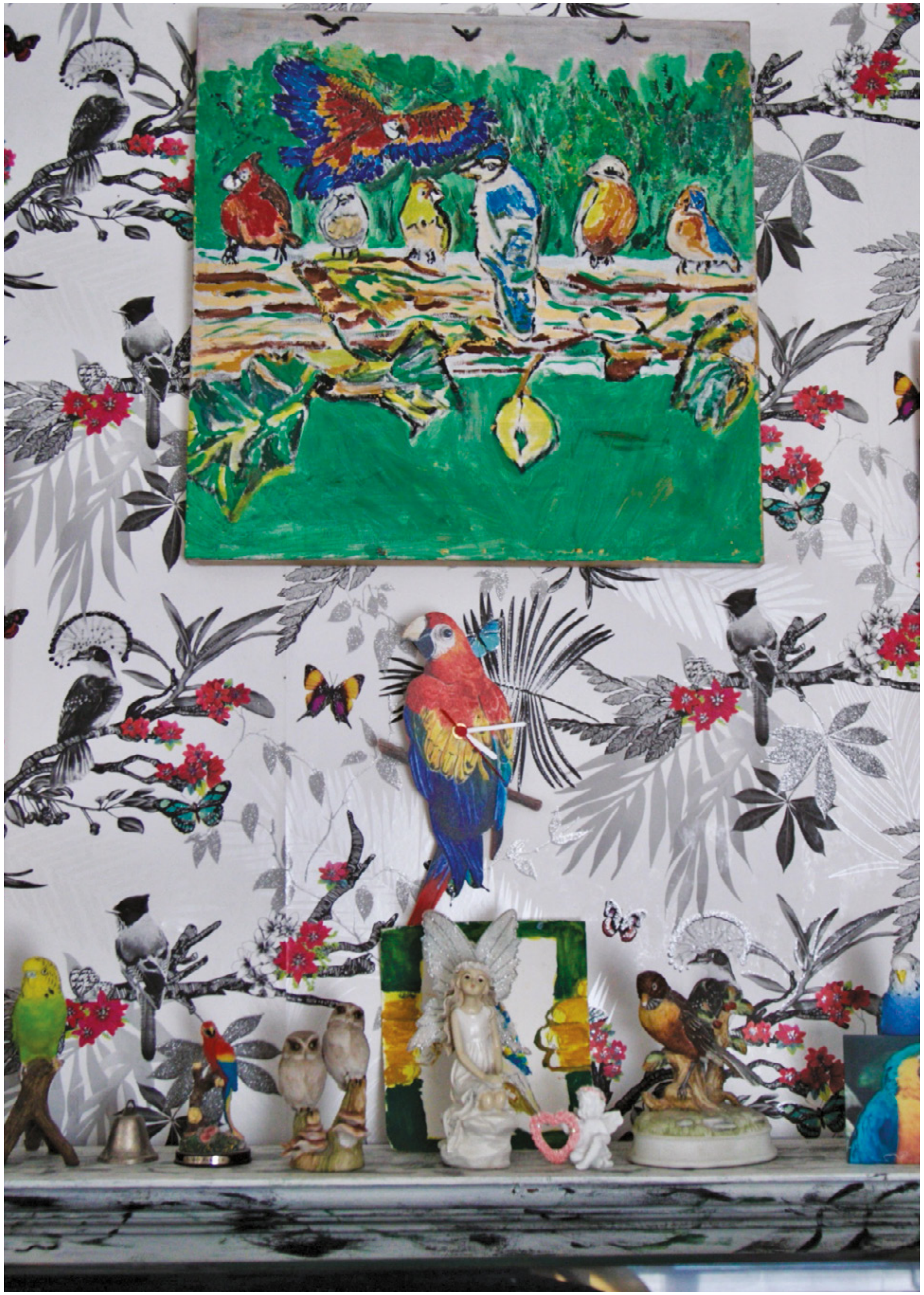
In my culture we say,
’All five fingers are not the same,
one is different.’
That’s what I was;
I wasn’t the same.
I was different.
I belong to somebody else.
I don’t know who.

It was a forced marriage.
My father said,
‘You have to marry.’
He was ten years older than me.
I wasn’t in love with him; I didn’t like him.
I thought, ‘How am I going to cope with him?’
When I went to his bed the first time,
I knew nothing.

My youngest was three or four months
When he went to foster care.
Two and half when I got him back.
I was relieved to have somebody,
To have someone to love.

In my culture,
People tell me, ‘You can’t do this,
On your own.
You’ve got to marry again.’
But I’m not getting married
To someone I don’t love.
Can’t do that.
Not now.





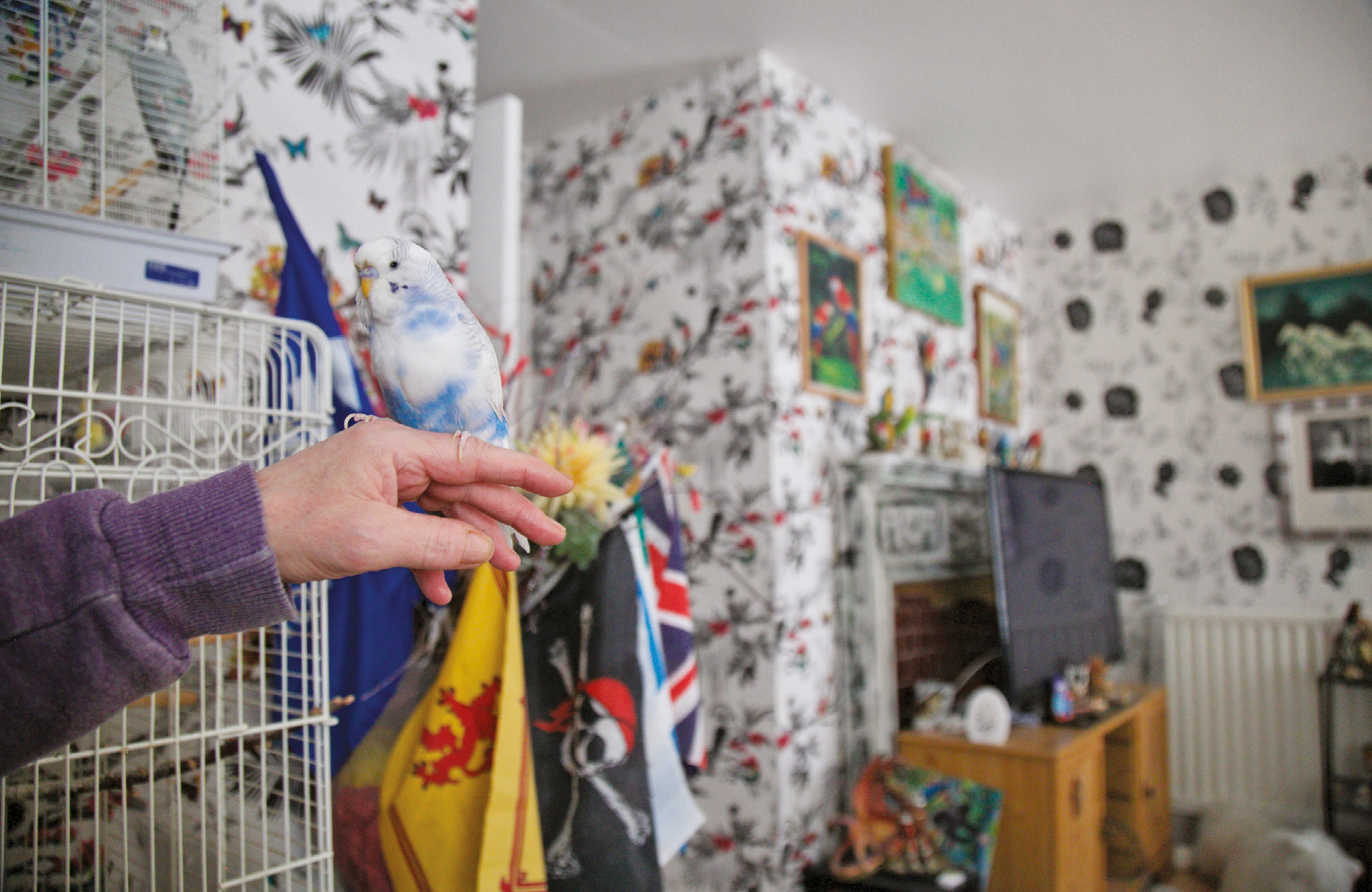
We got married – but it was a forced marriage because at that time the church didn't believe in sex before marriage, so I had to get married because we had sex. It was the church decided. I thought, that was it, the only option.

When he started beating us and stuff, I didn't talk to anyone about it. I kept it all inside. I didn't say anything. I've done a lot of that. Yeah, I've spent a long time keeping quiet.

I'd been abused when I was a child. He turned it against me. But nobody would hear you. Nobody would speak on my behalf. I lost three children. To me it was like a death but they was still there. At first when they were fostered I used to see them once a month. But it was horrible – especially for my daughter. She would scream and grab us. She didn't want us to go. I couldn't cry, I couldn't do nothing. I was grieving for years. Because I could hear them crying and they weren't there. I mean when Callum was taken off us his Christmas presents were still in his room.

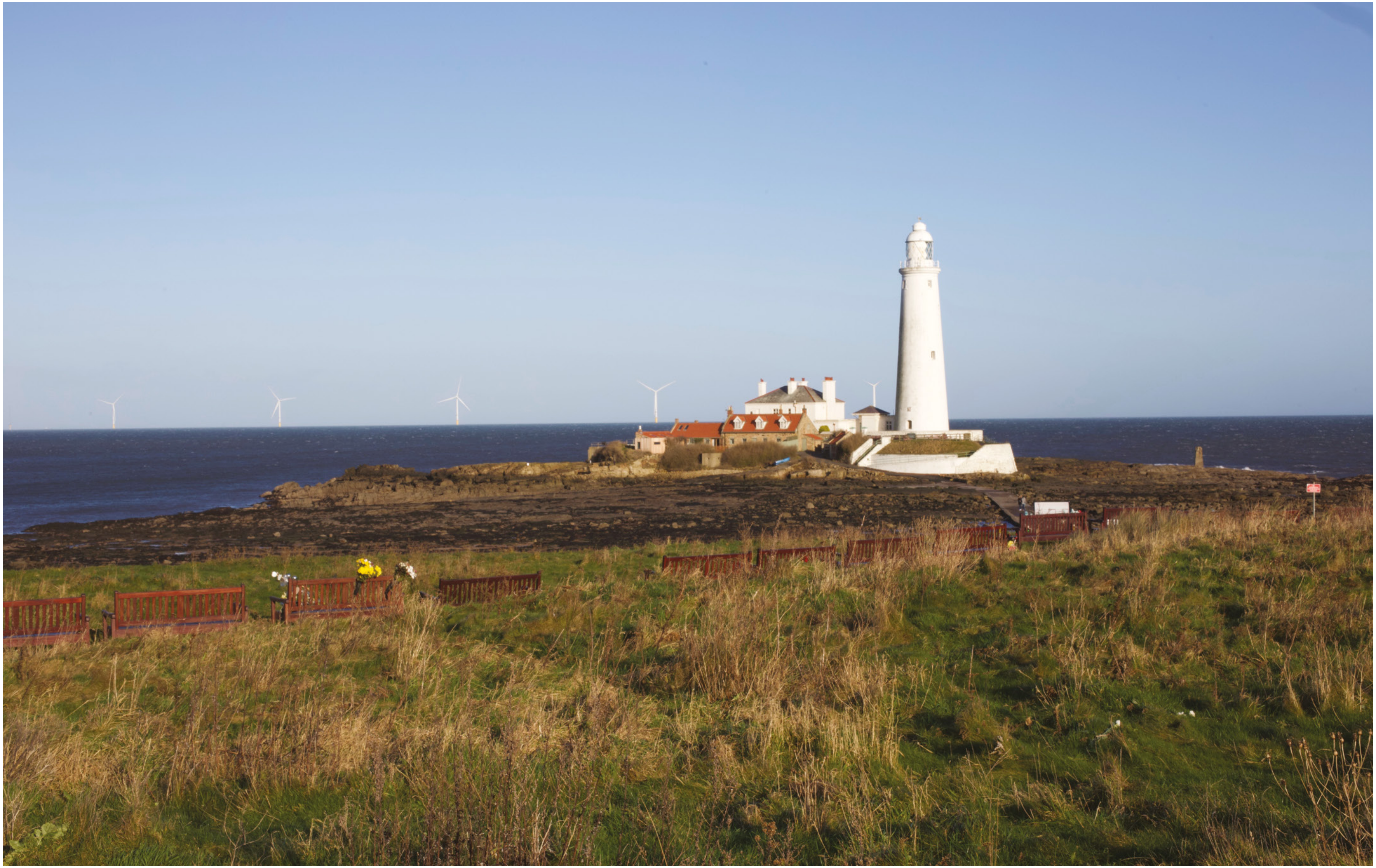
And life's better now because I can get out, go to Lawnmowers, do things. I'm a DJ as well and a drummer. I play in the glass orchestra. I write my own songs. And I write poems.

My current husband, Alan, he's lovely, really lovely. And he's mine! I met him when we were both volunteering. Well I just asked him to go out with us. I thought he was very well mannered. Nicely spoken. He's got three kids; we'd got that in common. I'd never really trusted anybody before – but I trust Alan.



"Social workers were watching me the whole time, telling me what to do."

"But when I did what they told me, that was wrong too. I couldn't do right for doing wrong."



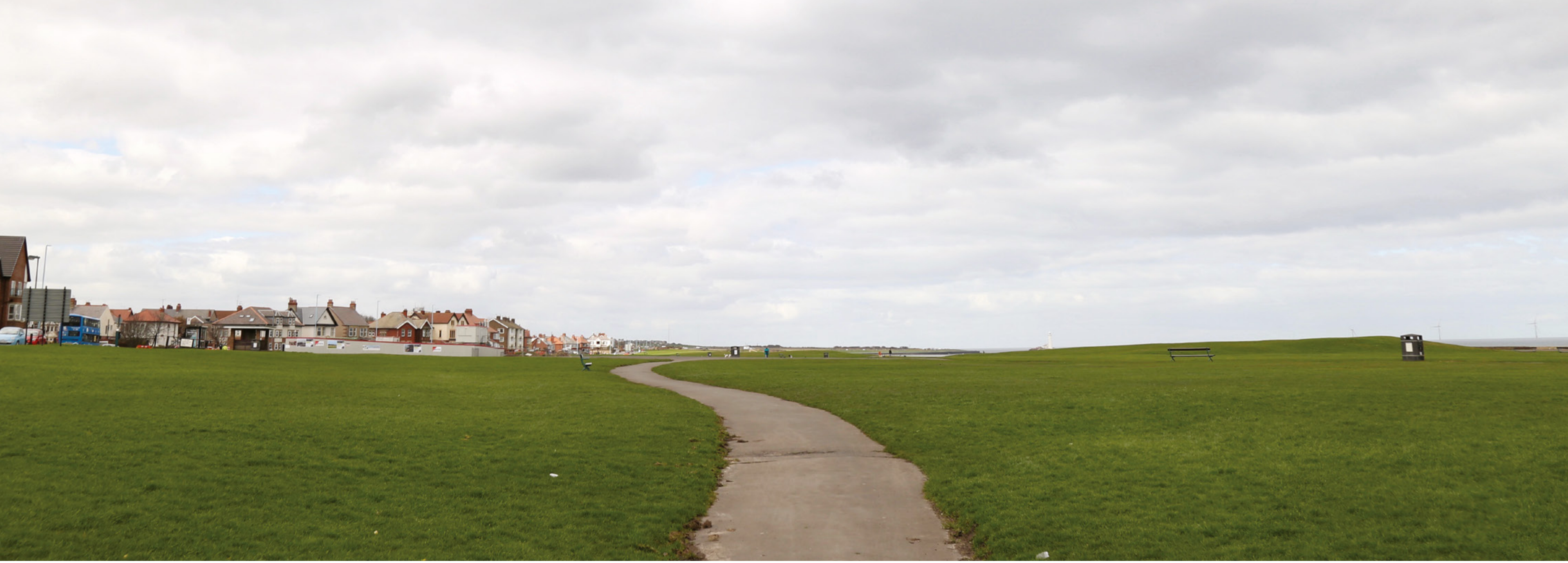
I was abused by my dad. He was a drinker and very violent. My real mam had a learning disability and epilepsy. She didn't believe us when I told her what had happened. She laughed. She laughed and then she left.

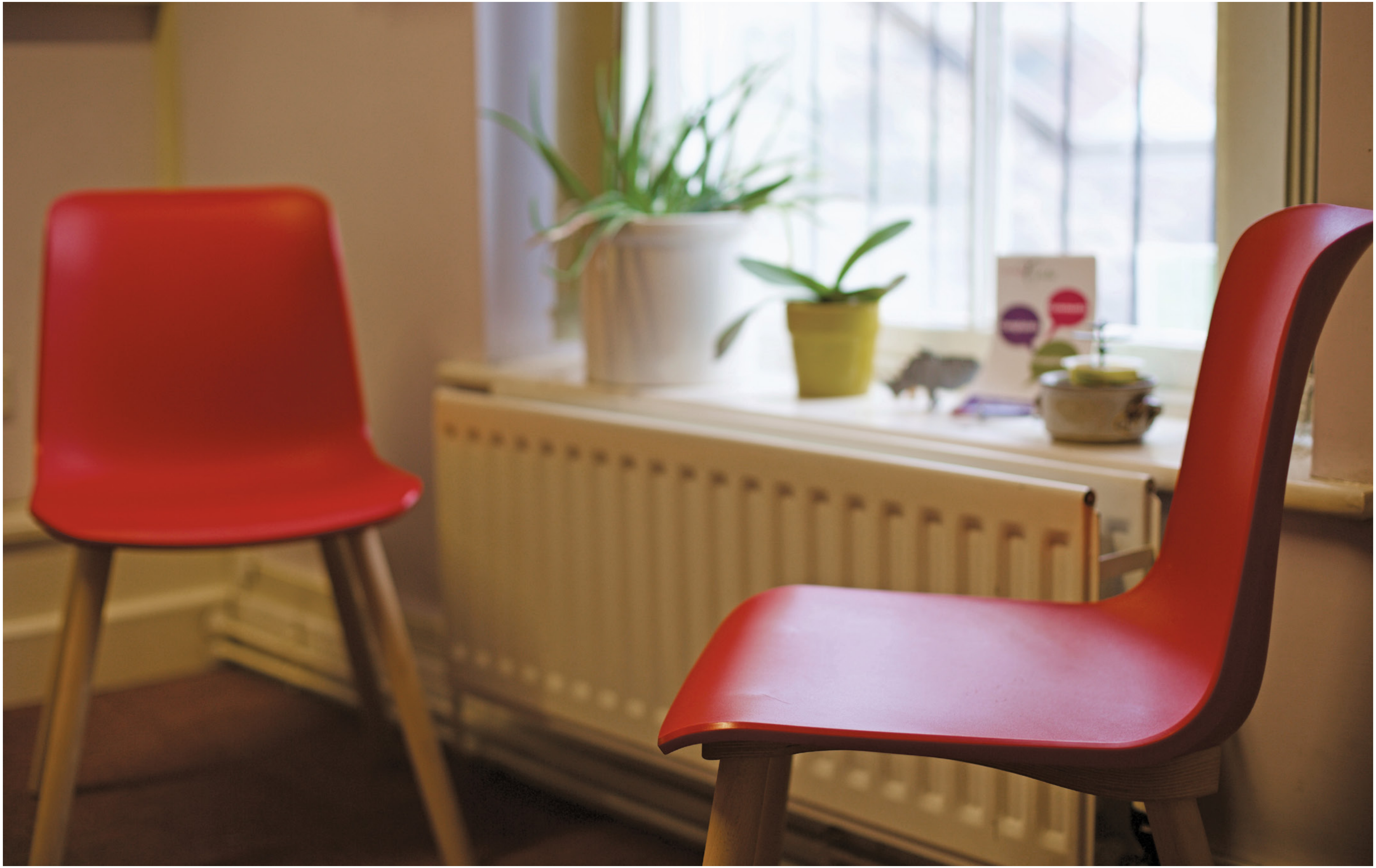
The school realised that things weren't right and I was adopted at 12. Then I was abused again by my adoptive mam. She was violent with me. Then I was abused again but that was rape. That was how I ended up with my son. The man wasn't a boyfriend but he was someone I knew.

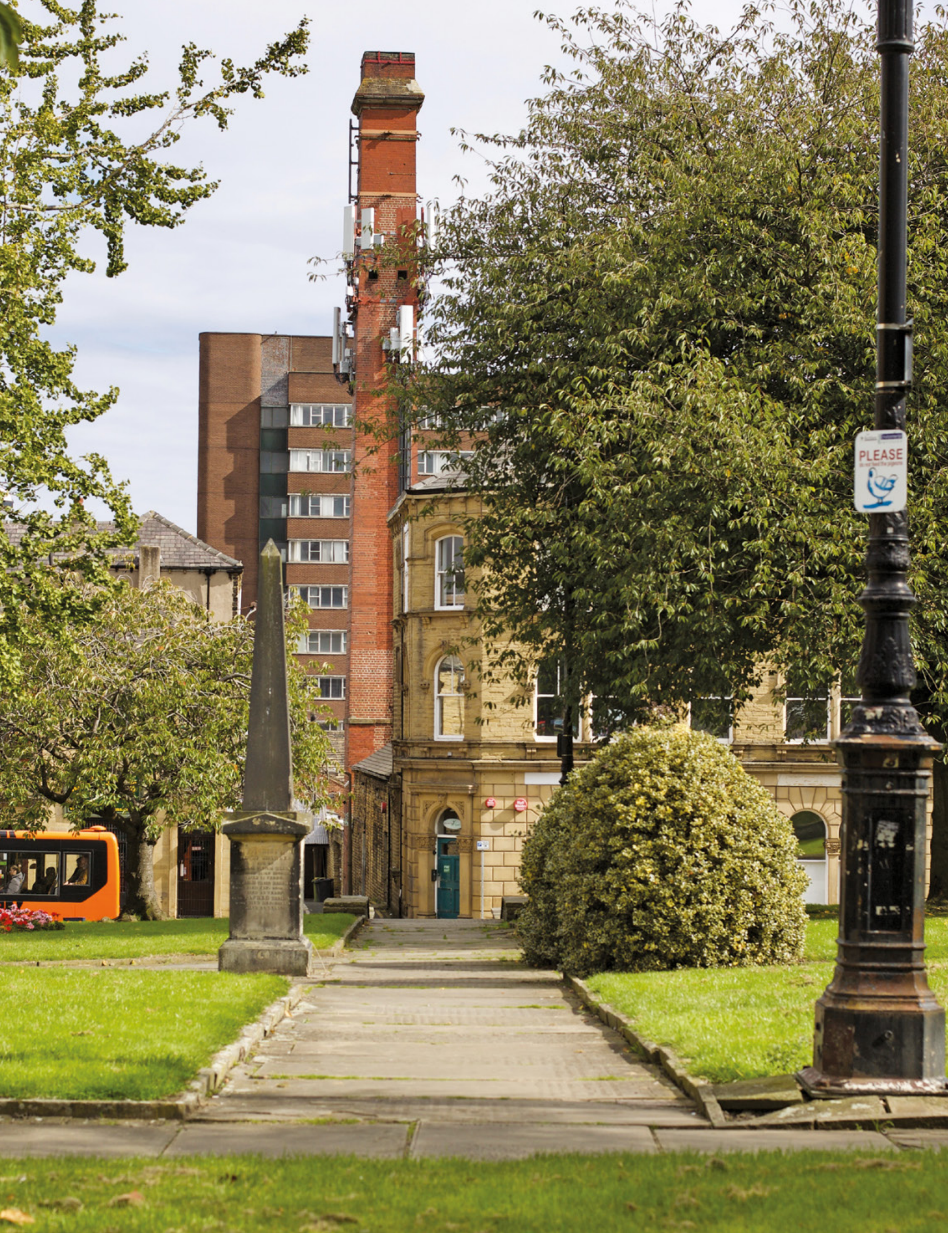
I was really, really bad when I was pregnant. I was at my adoptive mam's and she was being violent. When I had my son it wasn't safe me living there. It wasn't safe for a child to be in that situation.

When he got to two he came to be difficult. He had learning difficulties and he was hyper-active. He would pull my hair and hit me. Then it came to the point where I said, 'Well, he'll have to go into care because I cannae do it.' At that point I was physically harming myself. I felt I was in a dark room. It was like my brain was overflowing.

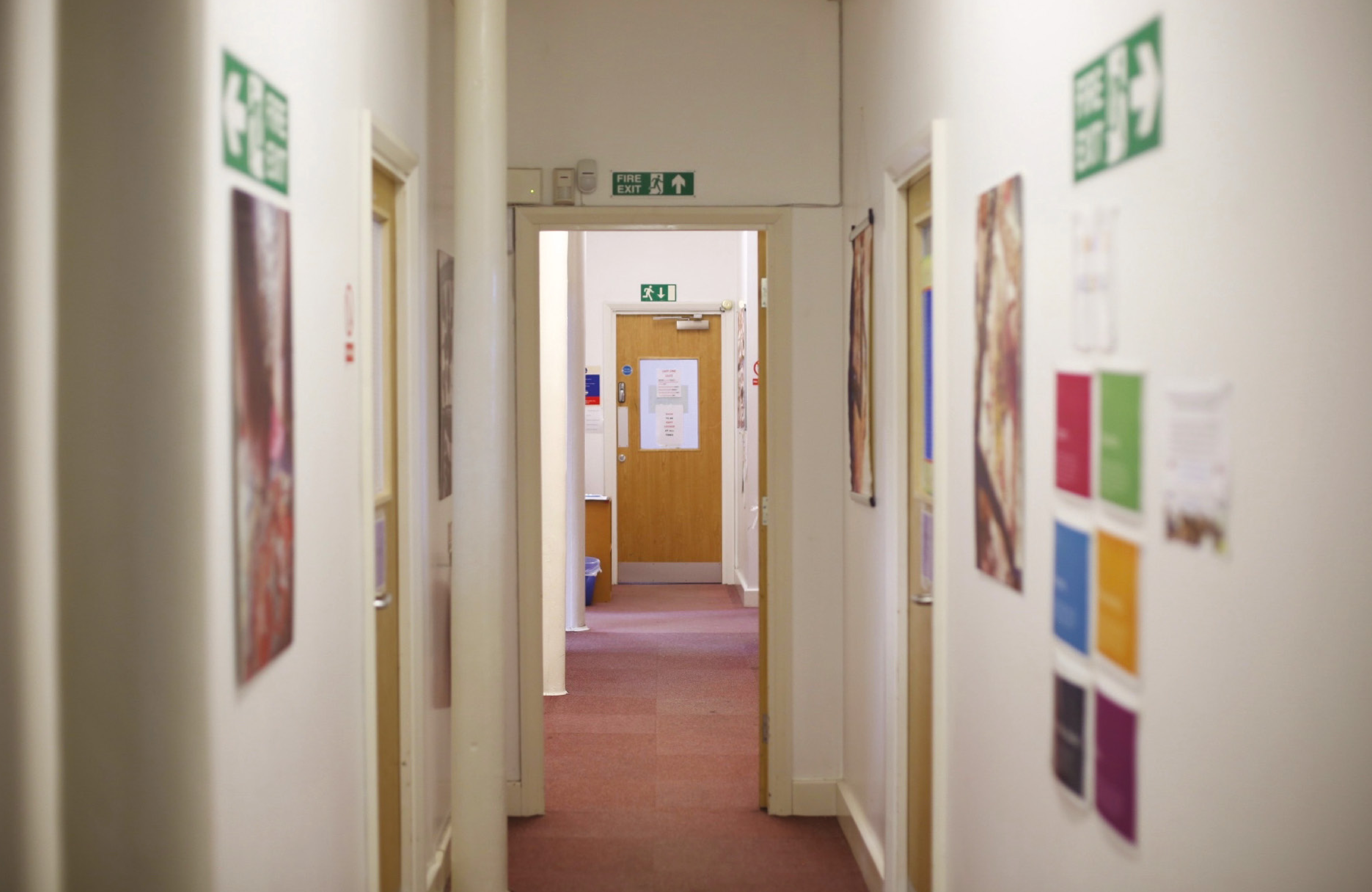
I rang the social worker and said, 'I love my son but I can't do this. I can't go on with it.' They said, 'We can put him into care if you want?' I had to do it; it was either that or being physically attacked. And it would have got worse. I told myself, 'Yes, it hurts. Yes, I'm going to be upset, but he's the most important thing in my life and if that's what I have to do for him then that's what I'm going to do.'







“I couldn't even tell them I had baby blues. The only person who knew was the midwife but she didn't say anything because she knew it would go against me.”

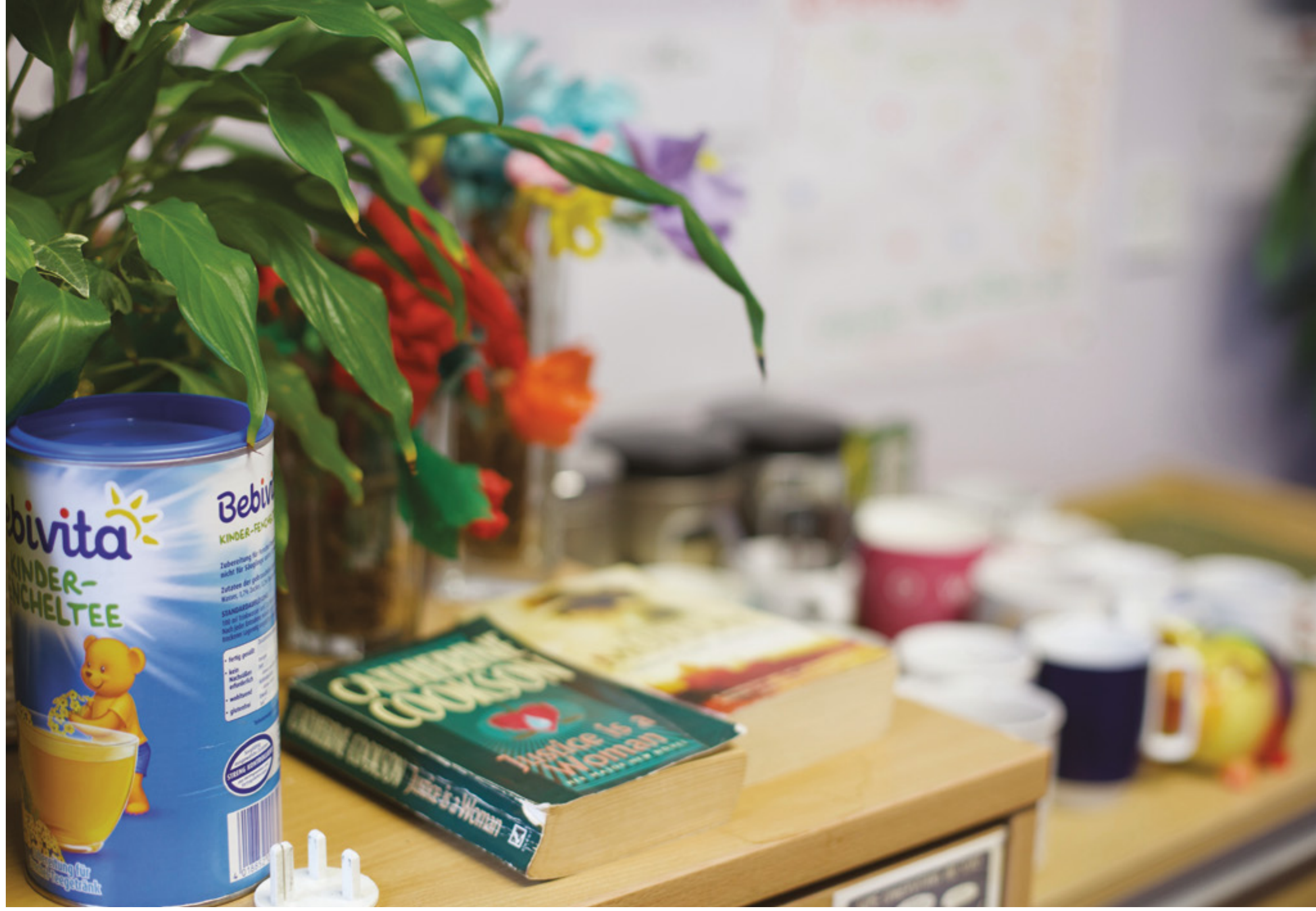

FIRE EXIT
FIRE EXIT
FIRE EXIT

Everyone knew

Everyone knew,
That once I give birth to my son,
I wasn't allowed to bring him home;
He wasn't coming back to me.
My family, people I know,
They all knew.

But I was doing the right thing.
I thought,
'I'll do what social worker's telling me.'
She promised me mother and baby unit,
More contact.
I believed her.
Signed papers I didn't understand.

But everyone knew,
Once I give birth to my son,
I wasn't allowed to bring him home;
He wasn't coming back to me.
Everyone knew,
Except me.



I knew I didn't want to be with my family anymore. At 17 I got a flat but struggled with looking after myself.

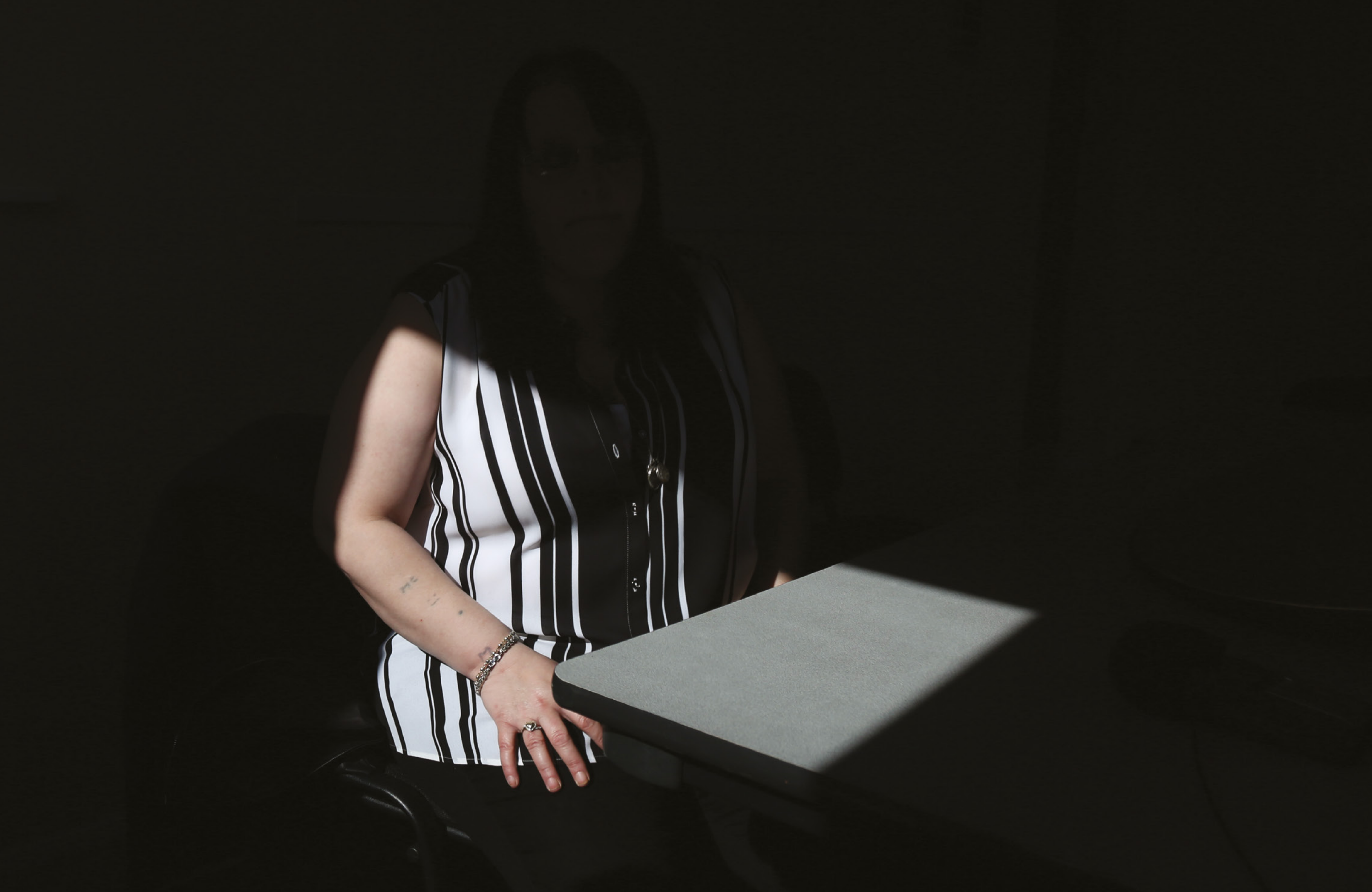
When I found out I was pregnant I had no one to turn to. I had a midwife and she got social services involved. The social worker told me a week before I was due that I wouldn't be able to bring my son home.

I was lucky because I got a couple of days in hospital with my son. But the morning after I gave birth the social worker came with my solicitor to talk to me. I signed papers I didn't understand; I don't know what I signed. I believed that once I did all the assessments, I could bring my son home. The day after I came out of hospital it went to court. I attended but I didn't understand the process. I thought it was a temporary thing because that was what she told me. But everyone else knew that he wasn't ever coming back to me.

When he was a couple of months – at a meeting round a table – I found out that he was going to be adopted with someone I only met about five or ten minutes before. I didn't have an advocate; I went through it on my own.

And then I got really ill and I got a support worker and they got me involved in the WomenCentre… It was a great feeling to know that someone understood but it were too late for me and my son.

I think learning disability played a good part in losing my child – not understanding things – but I do think my childhood has got a big part in it. That's one of the reasons my son went up for adoption.



“I asked for help and they wouldn’t listen. They said I didn’t fit the criteria. If I’d had more help I would still have my children at home.”

When I left home and moved to Newcastle my mum and my sister said they would give me a week and I’d be back but I proved them wrong.

I did catering and trained to be a chef until I had my children. I got married when I was 22. He was okay when I first met him. At the time I loved him. I hoped we would be together for a long time… I was married for a year. He used to control us and beat us up.

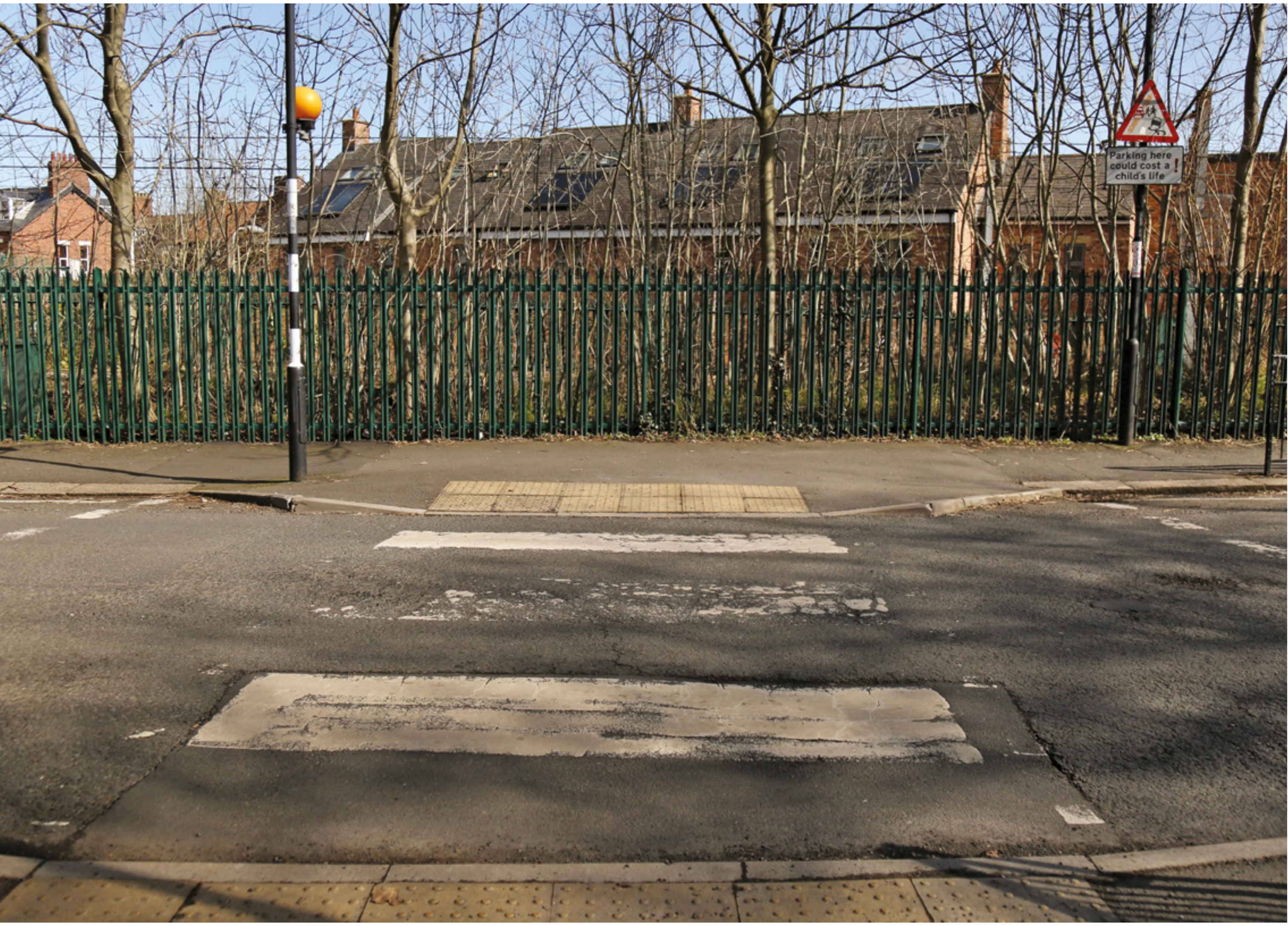
When we went to court, social services talked to the other professionals that were involved with the children rather than talking to me. They wouldn’t listen to me. I had to decide to put them into fostering. They said it was only temporary, but it ended up having a Child Protection Order on all three of them.

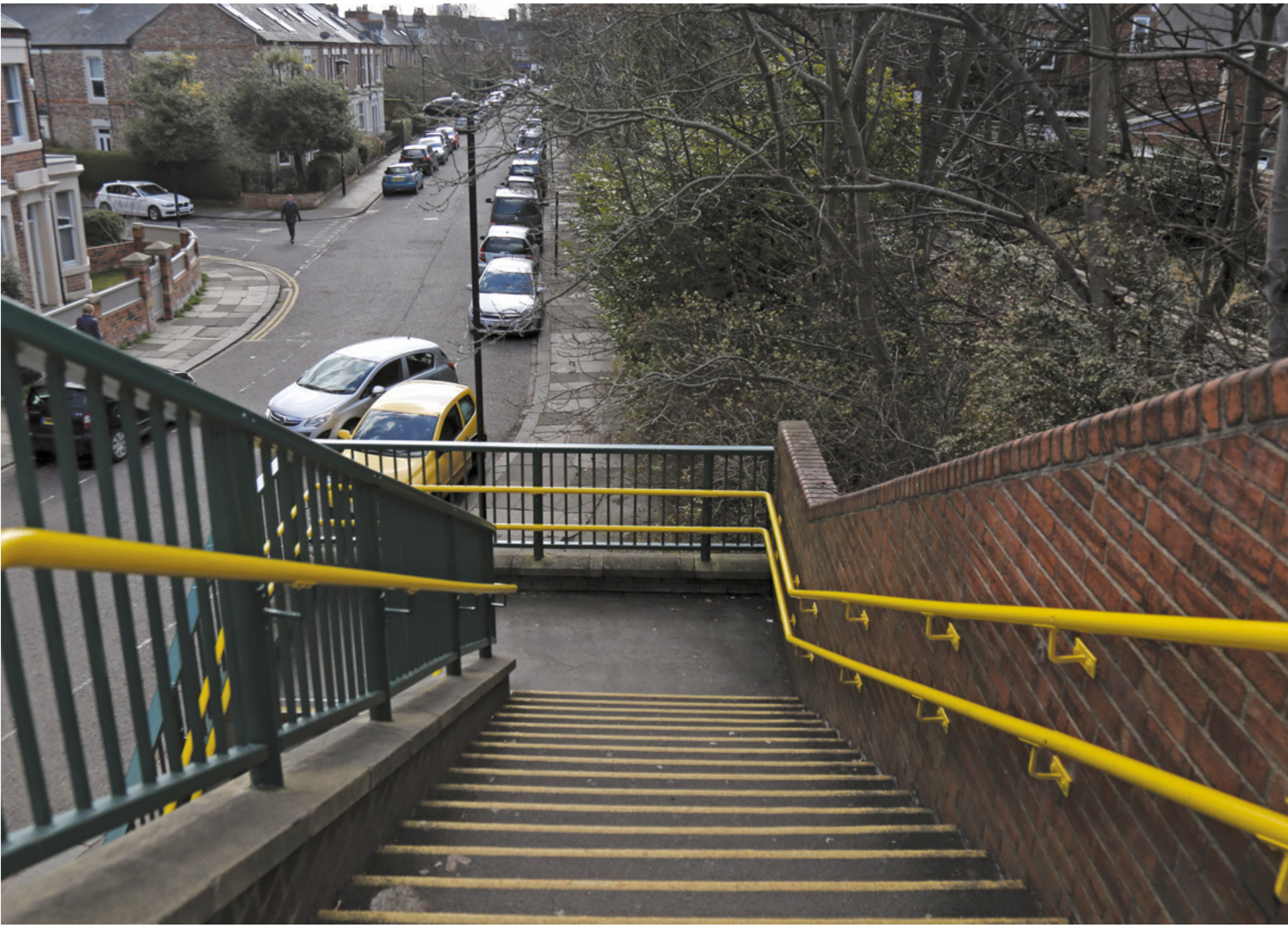
After the court I went back to an empty house on my own, with all the children’s things around me, a three-bedroom house. It was really hard.

My son’s home now ‘cause I got him back when he was turning 17. My middle one is in foster care. She’s 13 and she can speak now and write her name. I see her every school holiday. I take her to the park or for a meal and she really enjoys it and she never used to say it, but now she turns round and says, ‘Mama, I love you.’ My youngest one got adopted. I get a letter once a year. She’s caught up on her age now. She’s top of her class for dancing and for reading. She’s a yellow belt in karate.

I would love all my kids home, but I know I can’t have that.

“For the adoption I couldn’t get legal aid so I had to read my statement on my own in the Family Court.”


Parking here could cost a child's life



A hard journey

I always hoped I would have children. Yeah, yeah. My family was supportive, my mum, my dad, my sisters, my wife, my wife's family. I have three kids, three!

I met my wife when I went to Pakistan. Then we got married and she came here. We planned to have a big family.

I used to live with my mum and my wife and my kids. social services got involved because I started hitting my kids in the past and they separated me. I find it difficult when my kids are being naughty, especially when my relatives say they are naughty.

Now I live in supported accommodation. I still see my family but I have to be supervised.

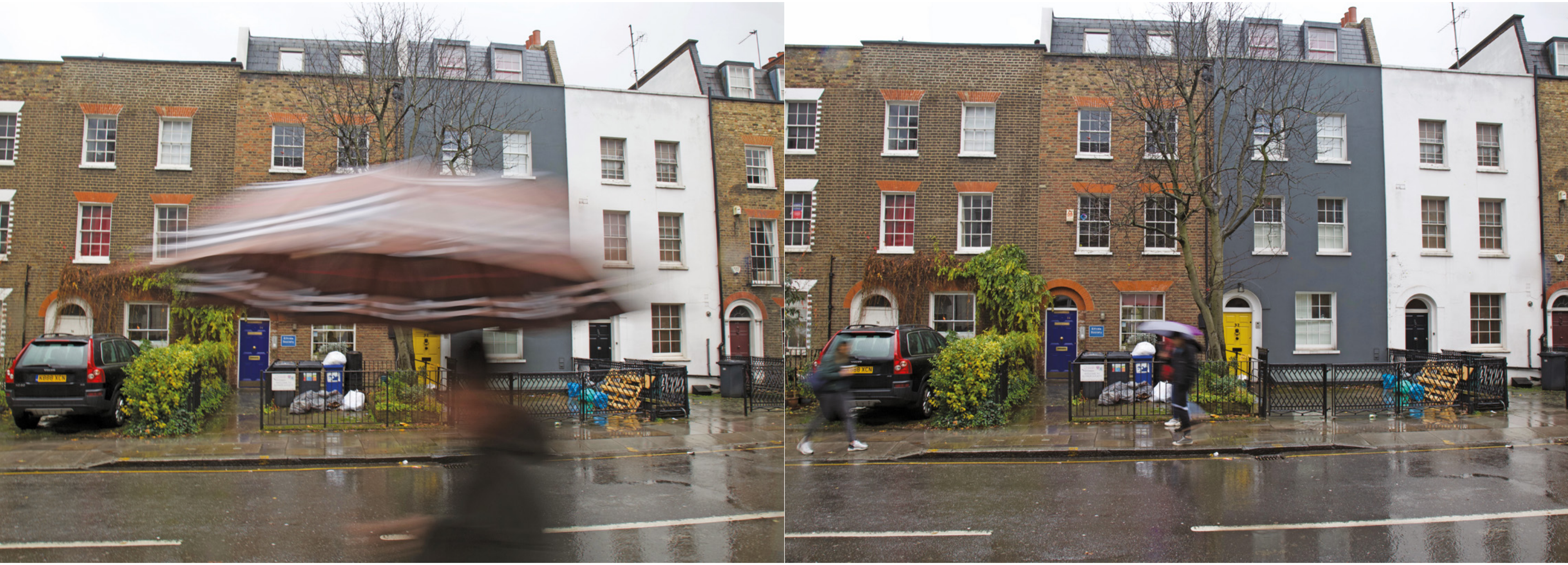
My social worker arranged support from Elfrida Parents' Group staff, for me to take one child out each week. I like going out with my kids, reading them books, playing with them. We have nice time, yeah.

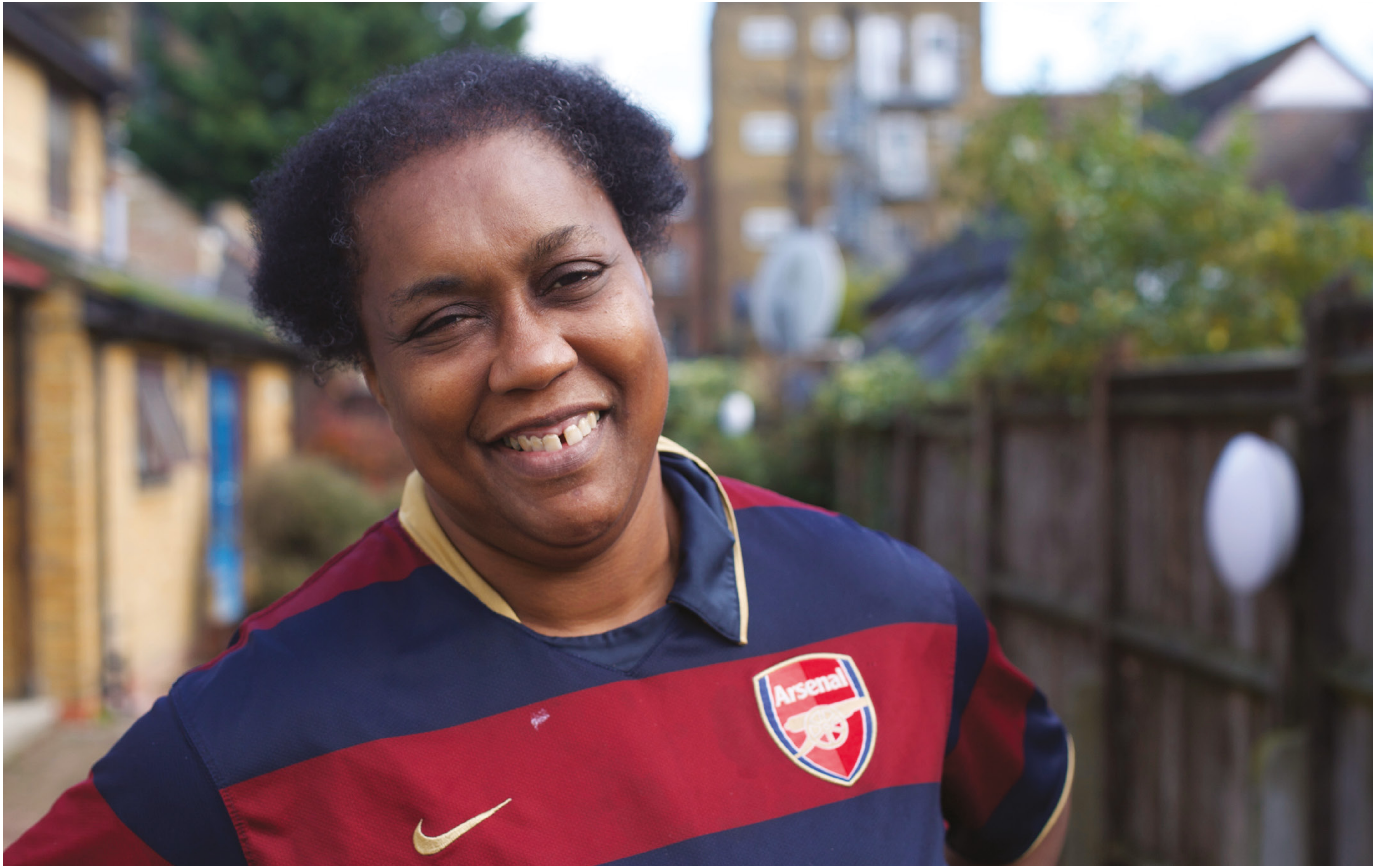
Without Elfrida it would have been hard to cope. My relationship is a little bit okay with my kids now. Things are okay with my wife… but it's been a hard journey, yeah. Some people say social services isn't good for them but, thank God, I have two different social workers and I have good relationship, good support from them. And I feel they want to help me keep my relationship with the kids.

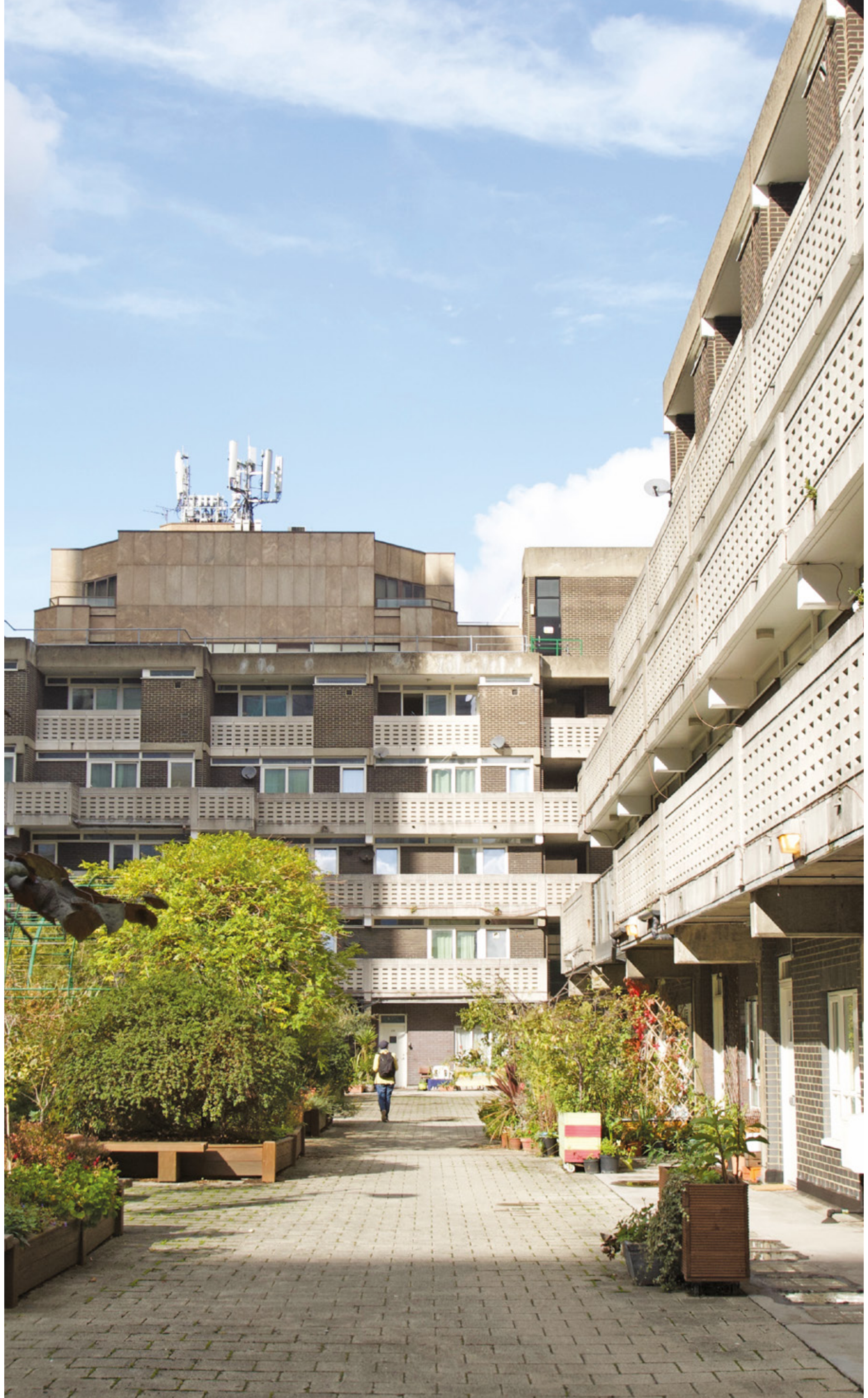
I wouldn't want to move back into the family home. I am happier in my supported accommodation. I can see my kids and I feel safe. I'm not worrying about losing my temper. I don't know about the future, take it day by day.

Learning-disabled parents should be given a chance. They should be given a chance, like I was given a chance.

“When I slapped my child, I feel bad. I know it isn’t right… but I can’t help it, getting frustrated and angry. I couldn’t help it, yeah.”




Arsenal



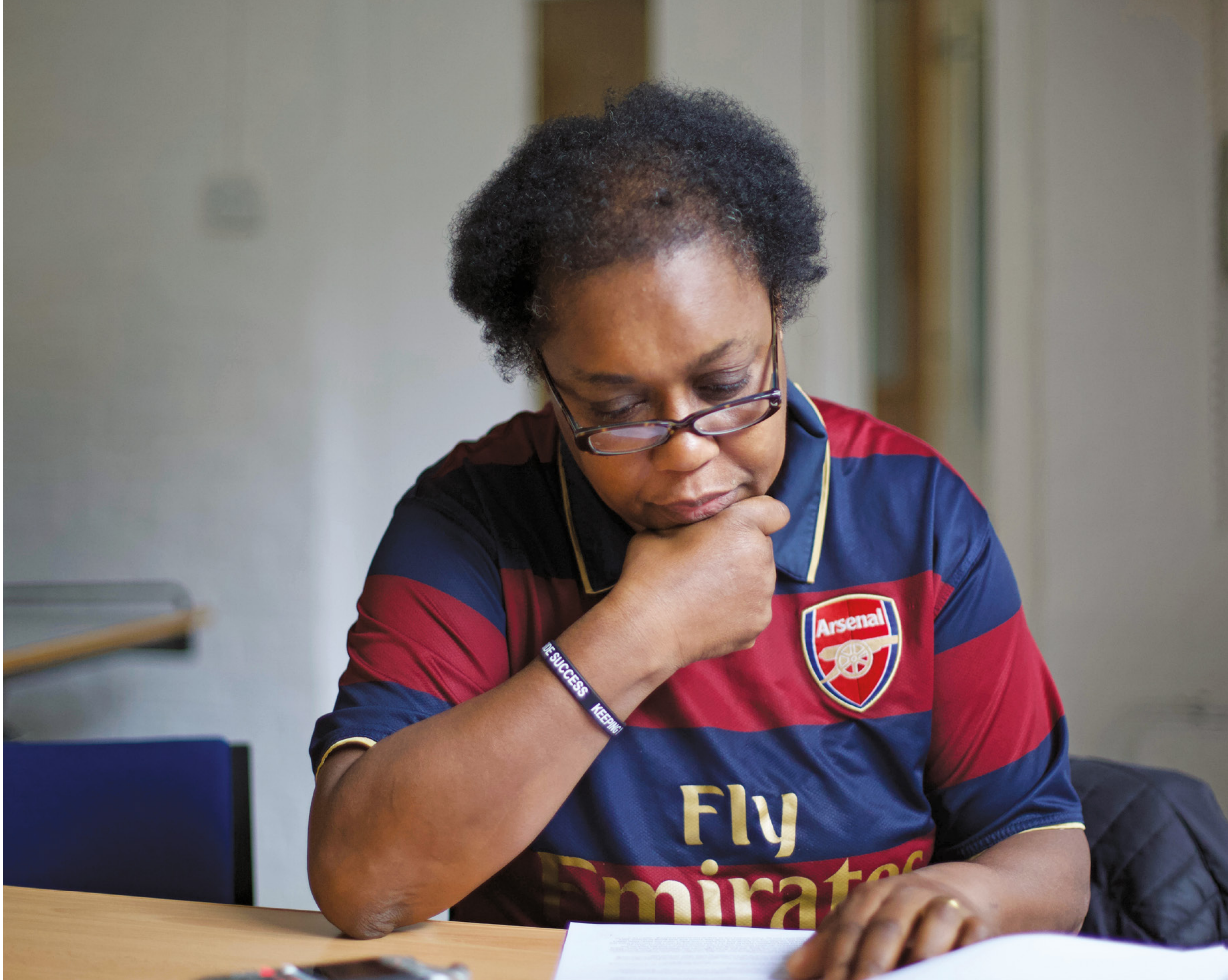
January 2019
The youngest one – he's got autism. He went into care when he was six months old and he's 15 now. They reckon I'll never get him back cause he's got autism. I've got a disability and he's got a disability. I wish I could get him back. I see him every two months and I can phone the foster carers whenever I want to.

"A friend of mine took her own life. She left a note. 'You took my child off me. I'm going to kill myself."

November 2019

I got a phone call on the Saturday, end of September. Foster carer phoned up and said they want to be moving and I can have Dexter back home living with me on the Thursday. Not even a week's notice. They said they'd been trying to get hold of the social worker for the last few weeks to tell them. They said, 'Do you want Dexter home?' and I said, 'Course I would love him home.' They said could I pick him up on Thursday and they were going to ring social worker on the Monday to confirm it. Social worker rang me up on Monday evening and she said, 'I hear you've got Dexter coming back to live with you and you've got to pick him up on Thursday after he finishes school.' And I said, 'Yes I do.' And that was it.

Social worker hasn't got any problems with him being back home. They done an assessment of me and Gary and he can stay. Dexter was on Special Guardianship. I've got to go back to court to get that cut off. Social worker said Dexter is happy at home. Dexter said he's happy to be with his brother and his Mum and his stepdad. The only thing that worried me was that he was missing school. But I'm happy. Oh, I'm happy he's back.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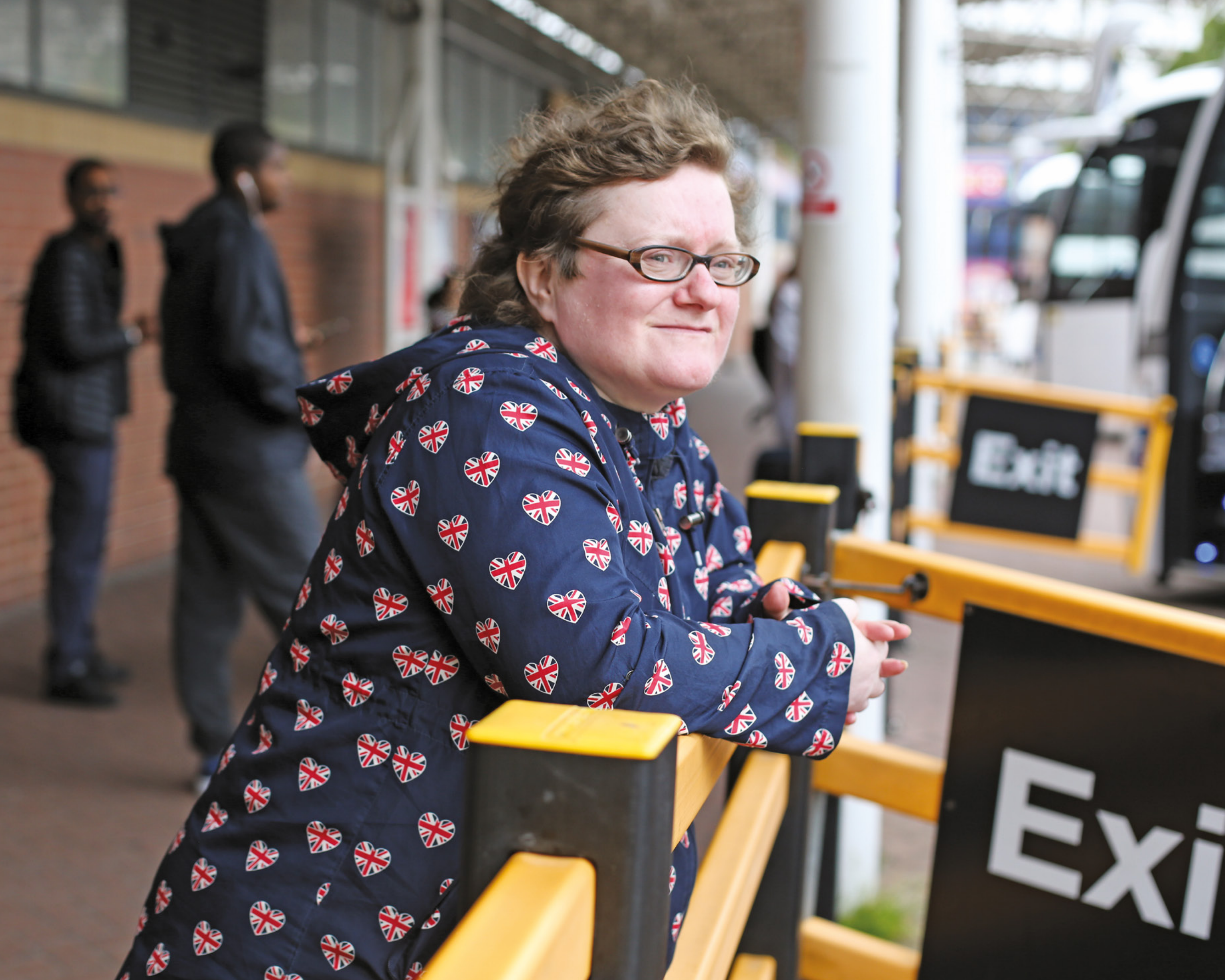
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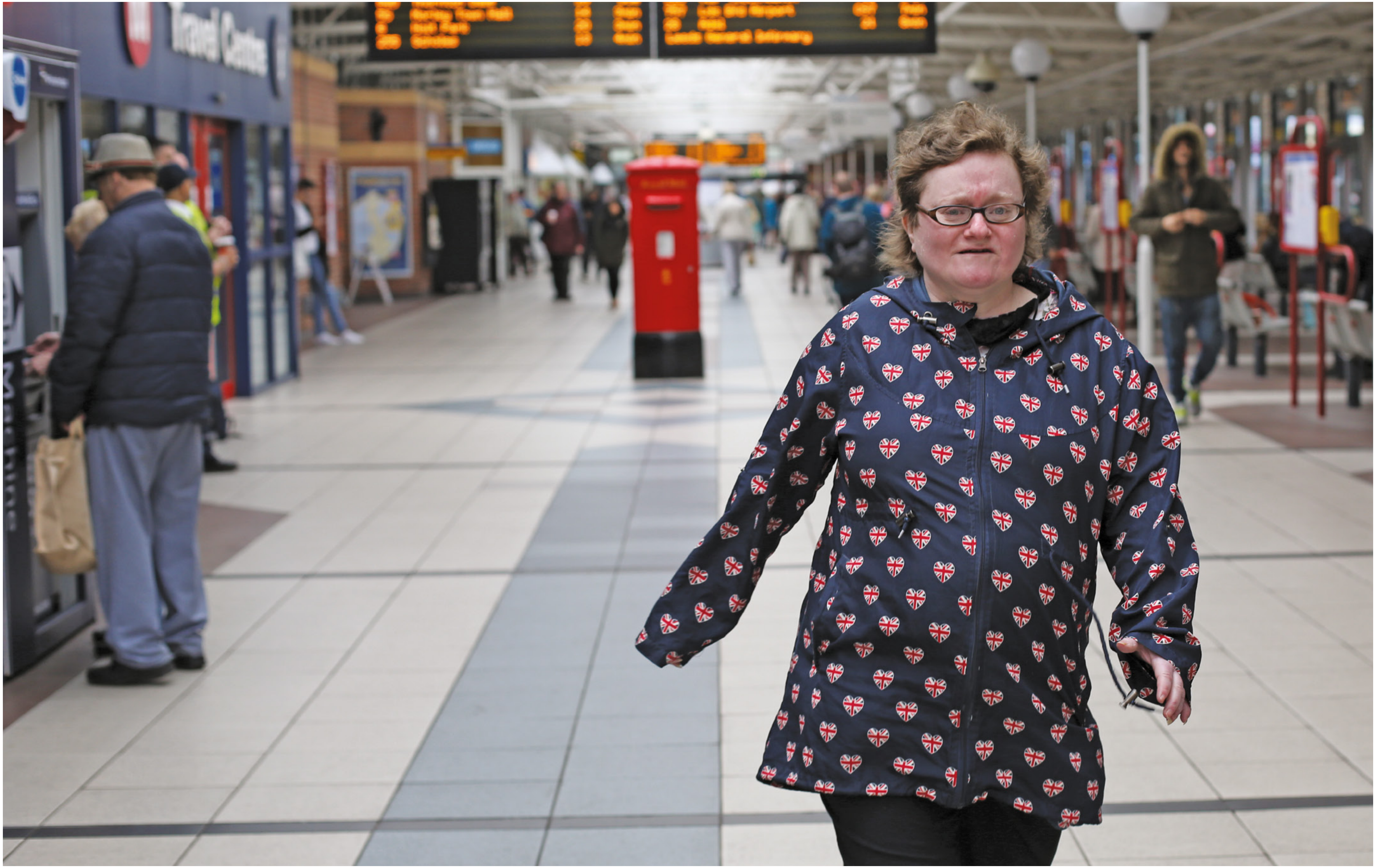

Travel Centre

“I met my partner through the Manchester Evening News personal ads. I read an ad from someone saying he had a learning disability, so I thought I’ve also got a learning disability and I sent a letter.”

My children have had eight social workers in their lives. They don’t stay with you for very long. Of those eight social workers there was only one nice one. She believed in me, but all the rest didn’t. They labelled me as someone who couldn’t parent.

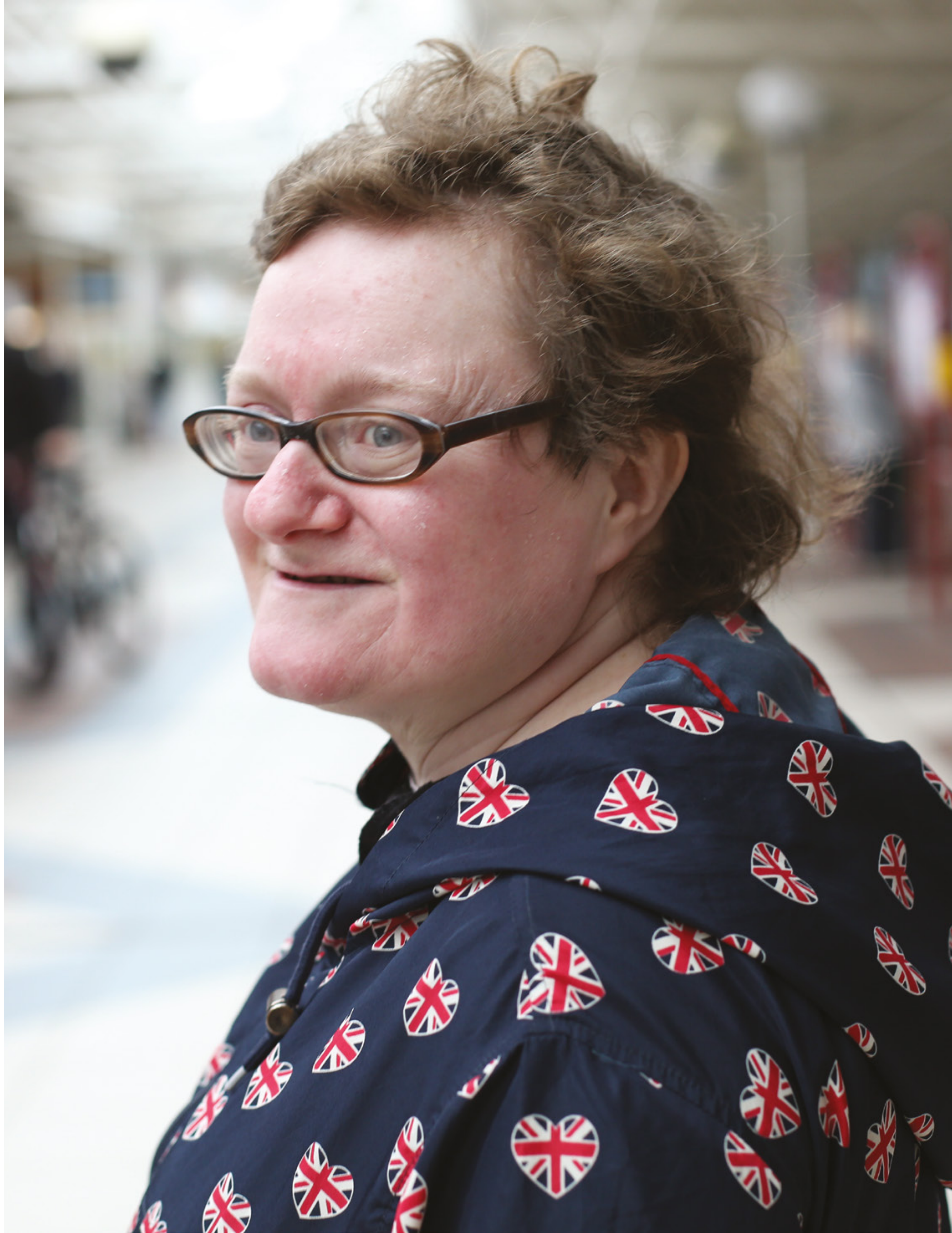
It was when I had my second son; she was called Sandra. She believed in us because her brother had a learning disability. She had a better understanding than any of the others.

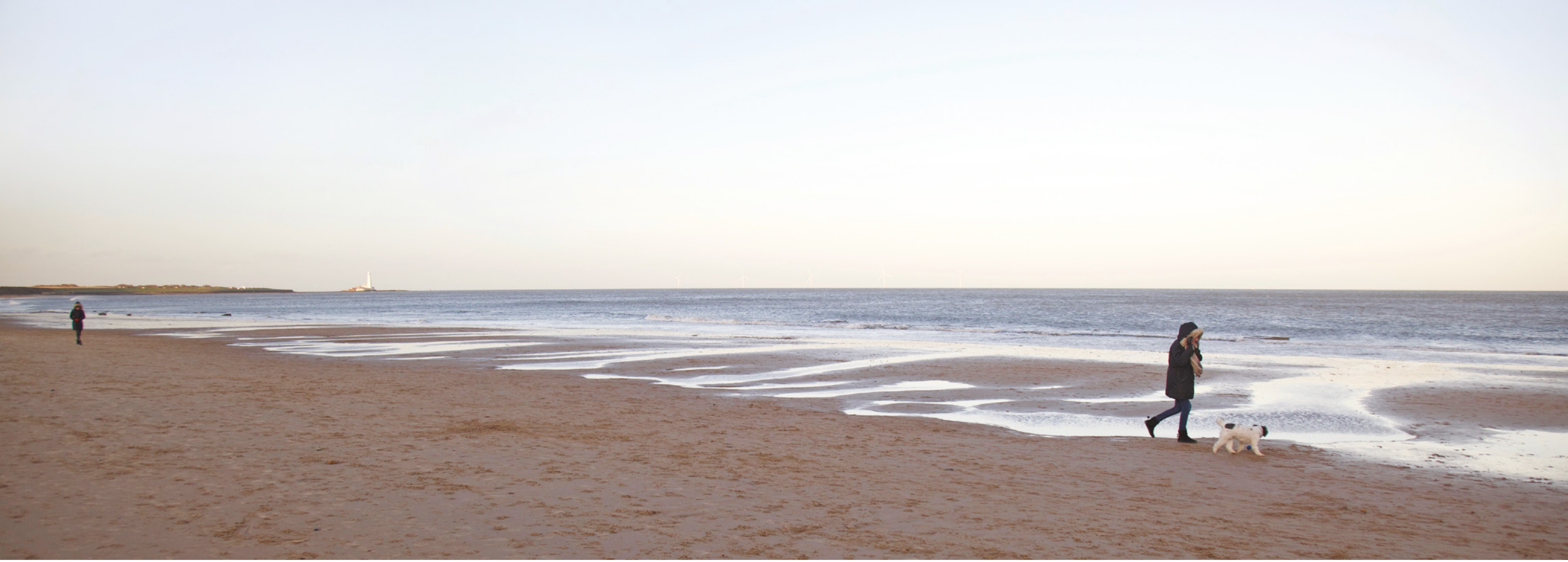
Social workers need more training; they need to understand and not stick labels on us. Learning disability doesn’t mean you can’t look after a child. They need to get to know us. Everyone works differently. Don’t judge us, see how we work. Assess us and see how we might respond. We’re just human beings like you who want to be good parents, but we’re not given the opportunity to be good parents because of people’s attitudes.

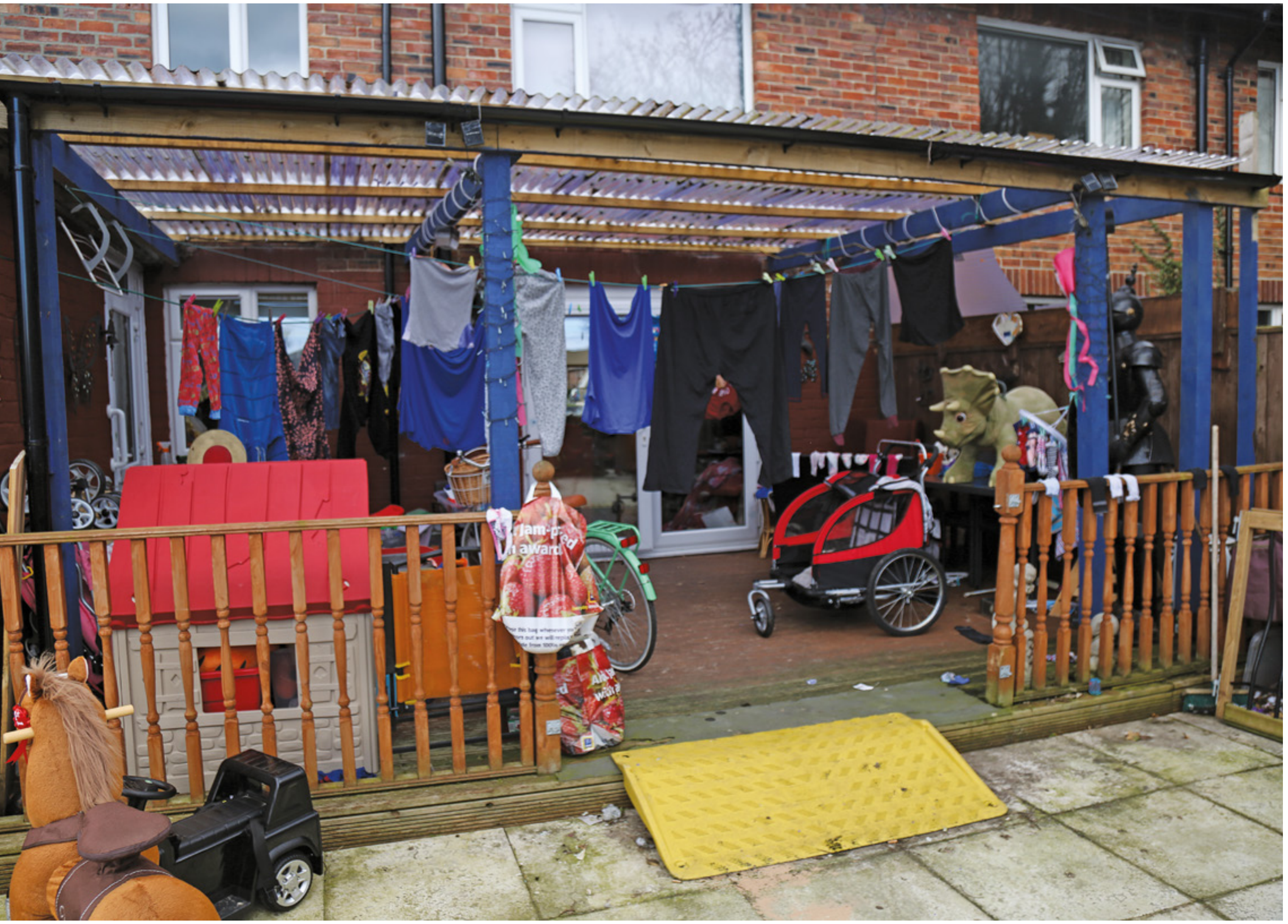
Now I work for Change three days a week and I help other people with learning disabilities deal with parenting issues. And we’re contributing to a training course for social workers about parents with learning disabilities. I do peer to peer support with learning-disabled mums who’ve had their children removed from their care and I try to support them.

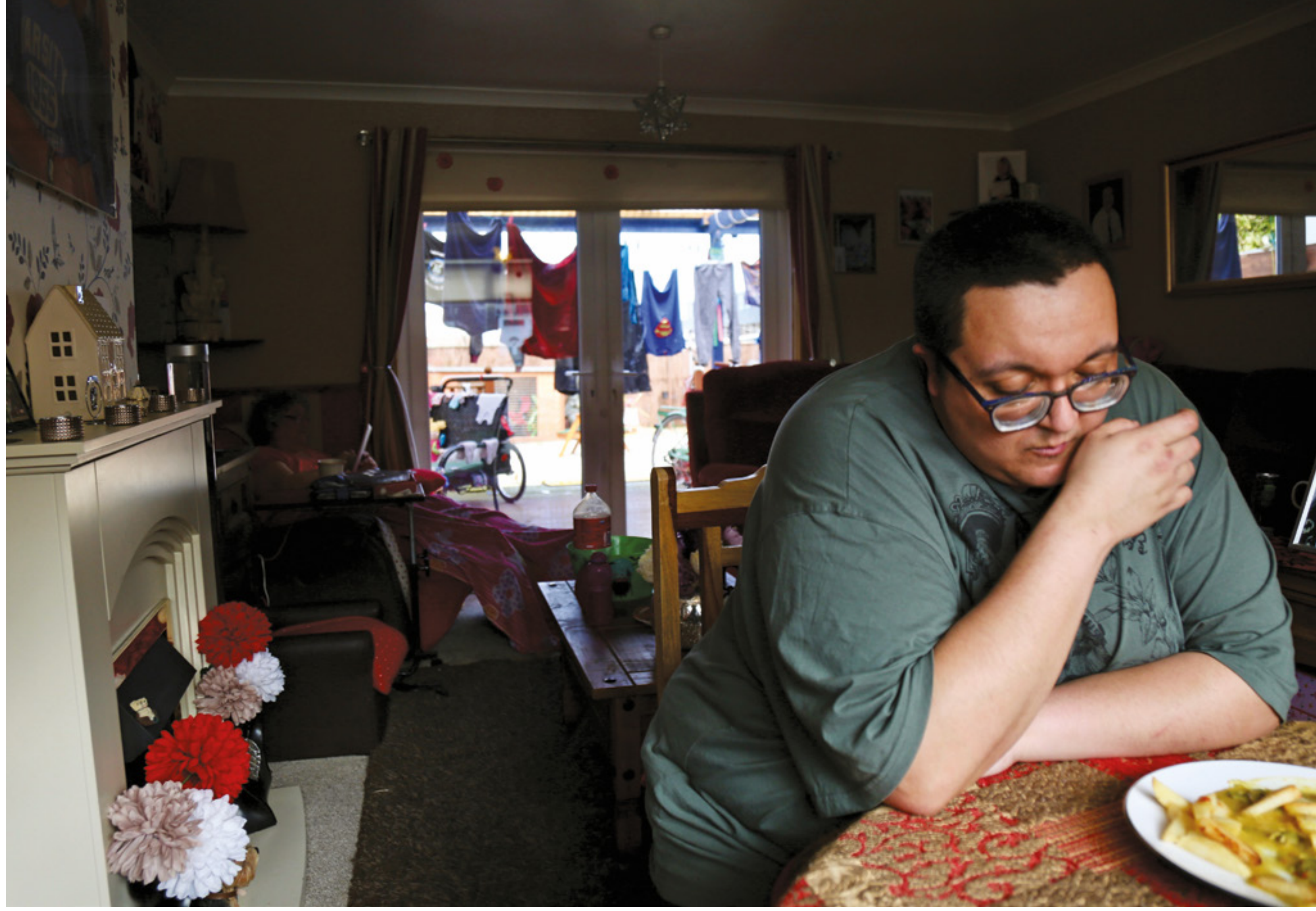
So what advice would I give a learning-disabled mother? Believe in yourself. Social workers will find out about the pregnancy because they usually do, so get information, get them to work with you. And if something doesn’t work, find the help. There’s loads of help out there.

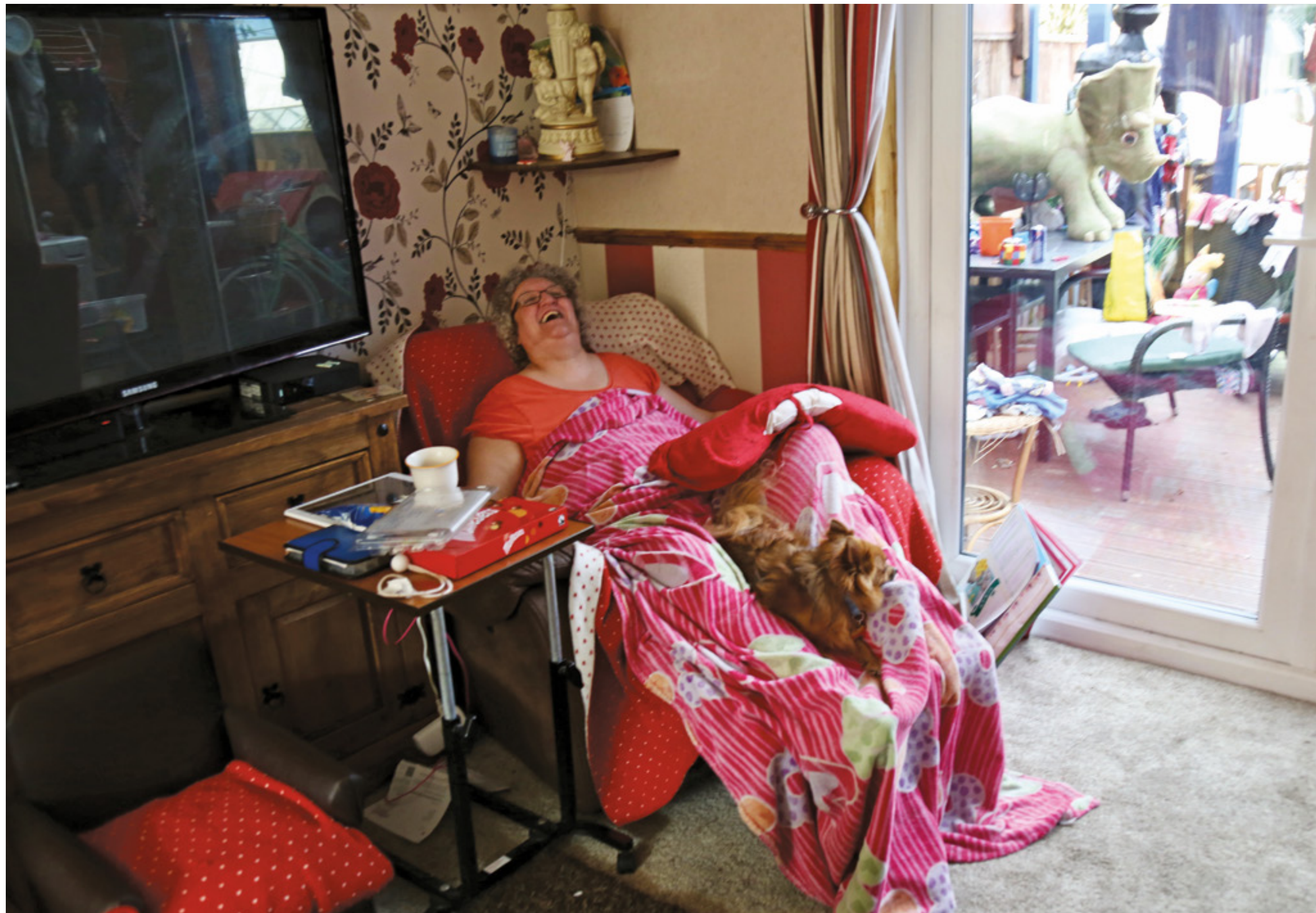
Parents without learning disabilities can be bad parents too but they get support. But if you have a learning disability, you’re just a bad parent. We want the same opportunities as other people.

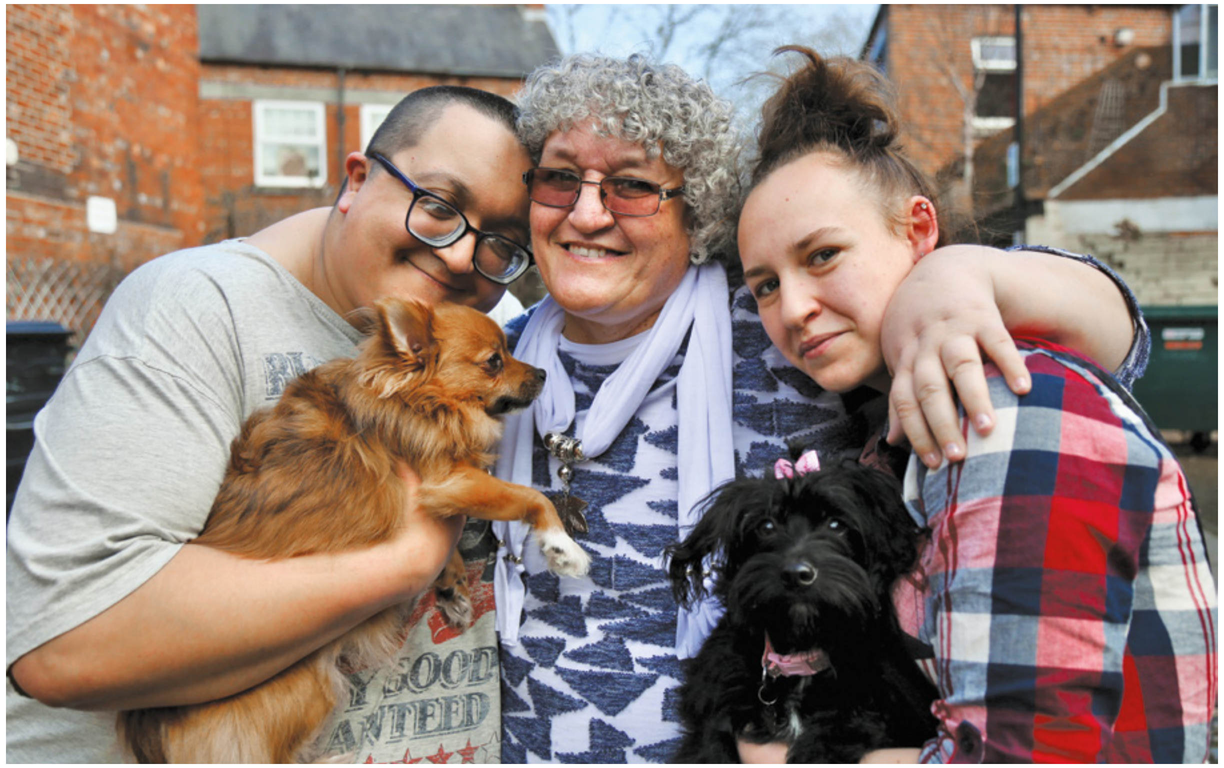












It's really hard to talk about my family. I loved my mum and my brothers and sisters; it was my dad. I just felt I didn't belong anywhere.

All I ever wanted in my whole life was a child to love. Of my own. I wanted to bring a child into the world and do everything different. And protect the child from the life that I'd had. I was just so happy to be pregnant. The doctors didn't want me to have the baby with me having a learning disability. They thought it would be too much for me but I proved them all wrong. And I ended up having two children, Matthew and Kirsty.

Matthew's whole life of going through school, I went with him, from five until he was 18. I went every day. I learnt more there than I've ever learnt in my life. There was one teacher, June; she helped me to believe in myself. I got taught in a way that felt safe, not like the school I'd been to. I couldn't read and write until then. June was a very special lady, very loving. I loved her and she taught me such a lot.

Now we all love singing and dancing. We do our acting together, we sing together. And I write songs. We got involved with pantomimes through a social worker. Matthew got a main part straight away 'cause he's very clever and he can remember all his words and he can sing and he can dance, even though he's a big man.

And after that Kirsty was Cinderella, she got Sleeping Beauty. She's played a few main parts. She's loved every minute of it. So there's a lot of good stuff you can get through social workers too.

"They don't think I can cope, because I have got a learning disability… it always came back to that."

As a clinical psychologist working in the NHS and social care over the last 10 years, I have held an interest in understanding the experiences of people with learning disabilities when they become, or want to become, parents. As an academic, I have researched these experiences, with an aim to improve services. As a therapist, I have worked to support the emotional well-being of learning-disabled mothers going through parenting assessments. And as a mother myself, I have noticed the similarities and discrepancies in my parenting journey and that of my clients, and been thankful I have not been scrutinised by other professionals when trying to manage a toddler tantrum.

It has been a privilege to collaborate with Mind the Gap since 2016 on their project into learning-disabled parenthood, with the academic research running in parallel with other threads of the project. Seventeen mothers and five fathers have been included in the qualitative research, using 'Thematic Analysis' to understand the patterns, or themes, across all of the parents' stories.

Whilst there has been wealth of parents' experience shared, the research has generated four main themes: (1) parents often feel in 'positions of powerlessness' in their relationships, many have experienced bullying or abuse in intimate relationships, and have felt let down and lost trust in others, especially professionals; (2) they face 'assumptions of incompetence', that professionals and others think they cannot be good enough parents; (3) parents fight to 'challenge assumptions and prove competence'; and (4) from these experiences of powerlessness and stigma, parents want to 'claim power' in their lives, speak up for their own and other parents' rights, often through parent peer support and self-advocacy.

The project has shown me the meaning of 'inclusive research'; working collaboratively with learning-disabled researchers and parents, to make sure our 'academic' research resonated with their lived experience. Working with an artist-led research team brought home to me what is really meant by 'research impact'; translating research into powerful stories, theatre and films, that could, I hope, genuinely influence professionals, tackle stigmatised attitudes, and help parents themselves to "take power back."

"We go out… telling them our story… so they can get the right services."

Dr Kate Theodore
Senior Lecturer / Clinical Psychologist

Working together with:
Laura Franklin
Trainee Clinical Psychologist
Royal Holloway, University of London

The entire experience of working on PAIGE and Daughters of Fortune has been fantastic and eye-opening. When I began working on this project more than three years ago, I was very inexperienced, both in life and as a writer.

As a learning-disabled man in my early twenties, the thought of having children had crossed my mind from time to time, though I'd never really thought about it seriously. After learning some of the hard truths about the statistics and meeting learning-disabled dads, I've begun to think it is less likely that I'll be a father in the future, though I am open to it.

I've lived a very sheltered life and hearing about some of the things that a large number of parents have gone through has really opened my eyes. The injustices some mothers with learning disabilities shared in the interviews were particularly harrowing. I realised that domestic violence and sexual abuse, which I had never heard discussed before, were often part of their experience. My most memorable interview was near the beginning of PAIGE and I can still remember all the details to this day. The most shocking element of it was not the story itself, but the very matter-of-fact plain way it was told, as if such harrowing incidents were everyday happenings. It really left a mark in my mind.

After doing this project and hearing how in some cases learning disability has played a big part in children being taken away from their parents, I firmly believe that education for young people with learning disabilities should change. At school and college learning-disabled young people should be taught not just sex education but relationship and parenting education. And they should be taught their basic human rights; that they have as much right as anyone to be a parent, and that having a learning disability should not be a barrier to being a good parent.

Daniel Foulds
Researcher

When Joyce Nga Yu Lee from Mind the Gap first approached me to work on the Daughters of Fortune project researching the experiences of learning-disabled parents I asked, ‘Do you mean parents of learning-disabled people?’ I quickly realised I had never considered learning-disabled people as parents in their own right. My reaction is a measure of the invisibility of learning-disabled parents and our assumptions that learning-disabled people can’t or shouldn’t be parents.

Working with Mind the Gap, Filmmaker Emilie Flower and Researcher Daniel Foulds, I have since had the privilege of confronting these assumptions by interviewing 22 learning-disabled parents in depth and meeting several more. All 22 of these were contacted through and supported by established organisations working with learning-disabled people in Yorkshire, Tyneside and London. We conducted an initial interview with each parent and transcribed the recording in a narrative form. We then returned to the parents with their written story and read it back to them. They were able to make any changes and additions before receiving a final copy of their story. Most also chose photos from those taken by Emilie and were given prints with their completed story. This book offers extracts from this process in the hope of illuminating the complexity of the lives of learning-disabled parents and supporting their visibility.

Despite this complexity and the emotional difficulty of recounting their often traumatic experiences, learning-disabled parents shared their moving and inspiring stories with warmth and generosity. We could see that we were conducting our research at a time when the support services upon which they had relied were being cut or were ceasing to exist. All the organisations we worked with were moving premises, restructuring with fewer staff, limiting hours, charging for previously free services and attempting to find more commercial funding sources. How long and to what extent they can survive with further funding cuts remains to be seen.

From this book it will be clear that learning-disabled parents, mothers especially, and their children are among the most vulnerable members of our society. People disappear when the services disappear; many learning-disabled parents and their children are already invisible and living ‘under the radar’, facing their challenges in isolation.

Part of the purpose of this book is to try to keep these parents, their children, and the organisations that work with them, visible and to show that with the right support they can thrive and offer inspiration to us all.

Mary Cooper
Researcher and Writer

Emilie Flower
Researcher, Photographer and Filmmaker

Our thanks go especially to all the parents who gave their time and told their stories with such generosity and courage.

We could not have completed the interviews without the help from the following organisations which, despite the many pressures on their time, made us welcome and facilitated our research.

Bradford People First
https://www.bradfordpeoplefirst.org.uk/about/

CHANGE
https://www.changepeople.org/

Cloverleaf Advocacy
https://www.cloverleaf-advocacy.co.uk/

Geordie Mums
http://skillsforpeople.org.uk/groups-courses/speaking-up-groups/geordie-mums/

The Elfrida Society
https://www.elfrida.com/

The Lawnmowers
http://lawnmowerstheatre.com/

WomenCentre – Calderdale and Kirklees
https://womencentre.org.uk/

Womens Health Matters
https://www.womenshealthmatters.org.uk/

Working Together with Parents Network
http://wtpn.co.uk

Through the Daughters of Fortune Project, Mind the Gap has developed a wide range of research and creative outputs that explore and share experiences of learning disability and parenthood. In addition to this publication, outputs include research papers, interactive workshops, performances and films. To find out more, go to www.mind-the-gap.org.uk, or call 01274 487390.

If you are affected by any of the issues raised in this book and want someone to talk to, please contact Family Lives, a governmental helpline service, or any of the organisations listed in the acknowledgements.

Family Lives
https://www.familylives.org.uk/

Family Lives offers a confidential helpline service for families in England and Wales (previously known as Parentline). You can call them on 0808 800 2222 for emotional support, information, advice and guidance on any aspect of parenting and family life. The helpline service is open 9am – 9pm, Monday to Friday and 10am – 3pm Saturday and Sunday.

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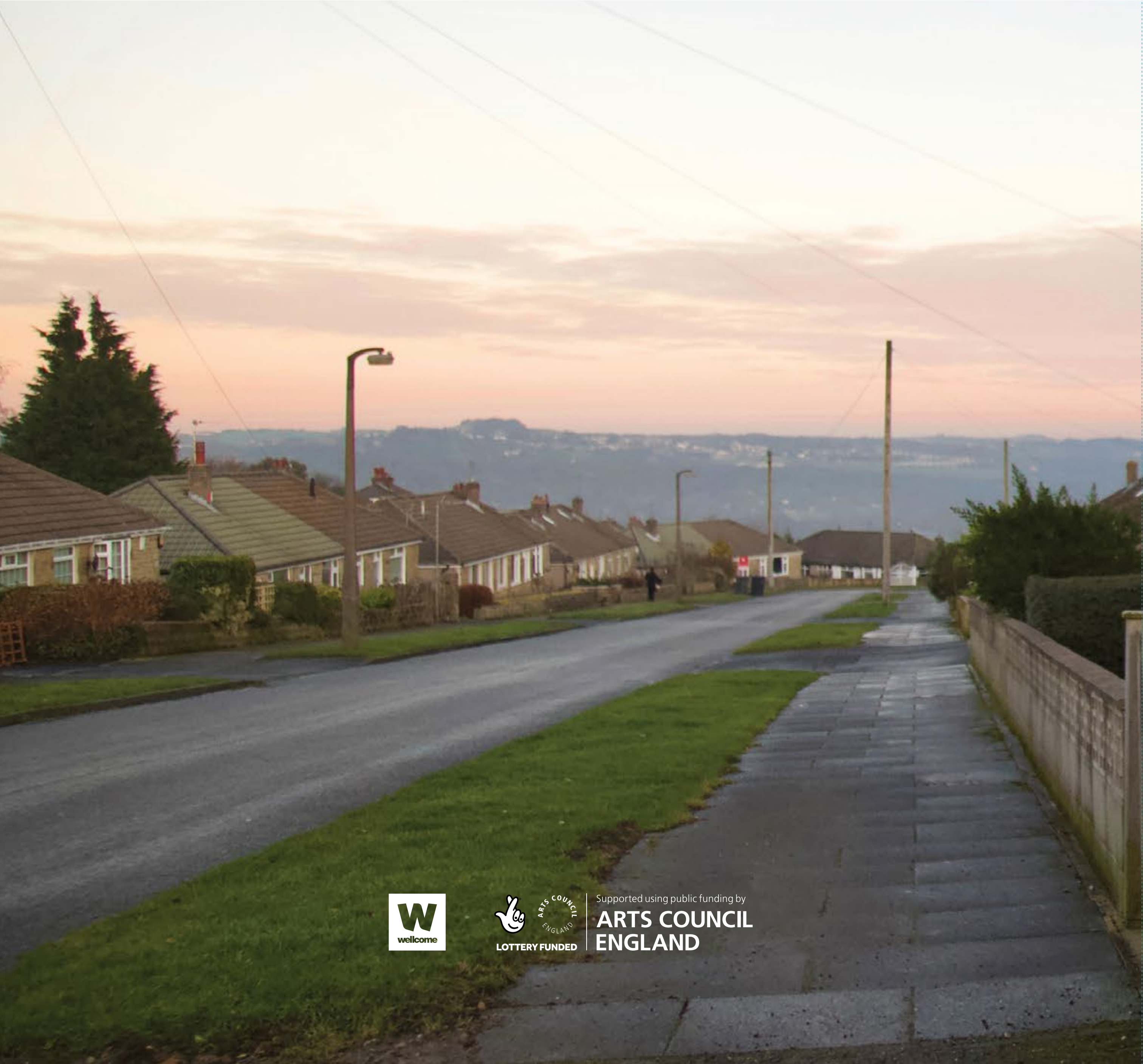

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