MY	1.	GO TO NURSERY
CHILD	2.	GO TO SCHOOL
HAS		BE RESPECTED
THE	J.	FOR, AND IN,
RIGHT		THEIR OWN
TO		DIFFERENCES
	4.	BE TREATED
		AS AN INDIVIDUAL
	5.	BE WHO THEY
		NEED TO BE
	6.	BE LOVED
	7.	BE HAPPY
	8.	BE SILLY
	9.	BE CARED FOR
	10.	BE WANTED
	11.	BE HEARD
	12.	BE UNDERSTOOD
	13.	BE SAFE
	14.	FEEL SAFE
	15.	MAKE MISTAKES
	16.	SHOW EMOTION
	17.	HAVE AN OPINION
		LEARN
	10.	

## SPECIAL RIGHTS

. LEARN MY NAME

2. DON'T MAKE
ASSUMPTIONS
ABOUT MY CHILD,
ASK ME

3. LET ME COME INTO THE ROOM

- 4. DON'T JUST LISTEN, YOU NEED TO HEAR ME
- 5. DON'T IGNORE MY CHILD
- 6. DON'T ASSUME
  MY CHILD IS
  NAUGHTY, ASK ME
  TO KNOW MORE
- 7. STOP WANTING PERFECTION
- 8. PLEASE UNDERSTAND,
  IF MY CHILD HASN'T
  SLEPT THEY WON'T
  HAVE A GOOD DAY
  9. BE PATIENT

THINGS
THAT
NEED
TO
CHANGE

OR TO CREATE MY IDEAL NURSERY...

Emma McGarry and Adam J B Walker in collaboration with children, parents and staff from the Portman Early Childhood Centre and Serpentine Education.

RIGHT

SPECIAL RIGHTS

CONTENT

This publication brings together multiple different voices. It can be read as a conversation between parents, children, artists, curators and early years workers.

PHOTOGRAPHS SHOW CHILDREN EXPLORING ARTIST INITIATED ENVIRONMENTS AT THE PORTMAN EARLY CHILDHOOD CENTRE.

KEEP ON UNPICKING, A STORY BY ADAM J B WALKER.

A RESPONSE TO
OFSTED'S 2017 REPORT
'BOLD BEGINNINGS',
BY EMMA MCGARRY IN

CONVERSATION WITH EARLY YEARS WORKERS AT THE PORTMAN.

REAL LIFE EXPERIENCES RECOUNTED BY FAMILIES AT THE PORTMAN.

FRAGMENTS OF SUPPORT FROM PARENTS.

DIFFERENT VOICES
AND RESPONSES
OCCASIONALLY INTERRUPT
THIS FORMAT.





- Edwards C Gandini L and Forman, G., The Hundred Languages of Children Reggio Emilia Approach -Advanced Reflections Ablex Publishing Corporation 1998
- 2 Nicholson S How NOT to cheat children: the theory of loose parts. Landscape Architecture 62 (1971): 30-4

This booklet is a celebration of difference, a collection of proposals for more inclusive schooling and an expression of solidarity with the many other children and families who face ongoing discrimination in the UK schools system. It has been developed by parents, children and early years workers from the Portman Early Childhood Centre, a state-maintained nurserv school in north-west London, in collaboration with artists Emma McGarry and Adam J B Walker, and was commissioned by Serpentine Education.

Collectively the group explored the potential of materialrich environments as sites of play and spaces for conversations about inclusion, disability, difference, needs and rights in the education system. Why and how are children with special educational needs and disabilities (SEND) being failed by the education system? How might adopting a special rights approach improve experiences for children with SEND? How can parents and carers come together with early years workers to create a network of support and solidarity?

Over a period of eight weeks, Emma McGarry and Adam J B Walker developed a series of play spaces in the outdoor area of the Portman nursery. Influenced by the idea of the environment as a third teacher from the Reggio Emilia preschools in northern Italy<sup>1</sup> and the theory of loose parts, these flexible play spaces featured a variety of objects including soil, clay bricks, metallic ventilation pipes, foam blocks and silver thermal blankets. Children entered the environment encountering and exploring the qualities and potentials of a range of familiar and unfamiliar materials. Through careful observation, reflection and collaborative planning, the artists, together with educators and curators, debated how best to support more than forty children who entered the space, carefully adapting the environment each week to better support children's sensory experiences and creative thought processes.

During a reflective meeting with early years workers at the Centre, we learned how several children, aged five and over and legally entitled to a school place, were being denied an education because primary schools had refused to place them. Amie Curtis, the Special Educational Needs and Disabilities Coordinator at the Portman, invited us to meet with the parents affected by these exclusions at the Centre's monthly coffee mornings. Over the course of four months we heard emotional accounts of the chaos wrought by the introduction of Education, Health and Care

Edwards C Gandini I and Forman G The Hundred Languages of Children: Reggio Emilia Approach - Advanced Reflections. Ablex Publishing Corporation. 1998. p. 199

Conderelli C and Wade G., Support Structures: A Co-production with Support Structure with James Lanadon. Sternberg Press. 2009

a manifesto for change.

5 Greenstein, A., Radical Inclusive Education. Concepts for Critical Psychology, Routledge, 2015.

6 Pogrund, G., 'Shameful' cuts hit children with special needs. The Times, 8 April 2018, goo.gl/LizHJa

7 Special Educational Needs funding in crisis. Teachers.org.uk. goo.gl/hCKmwK

Butler, P., Councils 'at breaking point' due to budget cuts and rising social care bills, The Guardian, 10 February 2017, goo.gl/xg8vy7

Drawing on the language of special rights<sup>3</sup> from Reggio Emilia preschools, the format of a book as a support structure<sup>4</sup> and the practice of creating utopian thought experiments through the work of critical psychologist Anat Greenstein. 5 we worked together to think beyond what already exists, in order to demand better support. We shared stories of the failure of the current system, discussed our ideas for alternative forms of education and collectively created

Plans, of children waiting over a year for a primary school place.

and of exclusionary practices in nurseries and primary classrooms.

Recent reports reveal that the experiences of families at the Portman are not isolated. Department of Education figures show that during 2017 there were over 4.000 children with disabilities or special needs who were left without a school place, with the majority forced to stay at home with parents or carers.<sup>6</sup> This figure has increased more than fivefold over the last five vears. Councils in England are facing an escalating financial crisis<sup>8</sup> following eight years of austerity and large cuts in government funding to local authorities. Lack of funding means that schools are cutting back on teaching assistants and special needs training, and consequently are unable to provide adequate support for children. Families of children with special needs are seeking legal action against the government because of their budget reductions.9

But the crisis has deeper roots than the recent cuts. For those children who do receive a school place, the reality of much mainstream school provision, which is increasingly defined by market principles, is a culture of standardised tests, competition and strict behaviour policies. These practices pathologise difference and create a disabling environment for students. 10

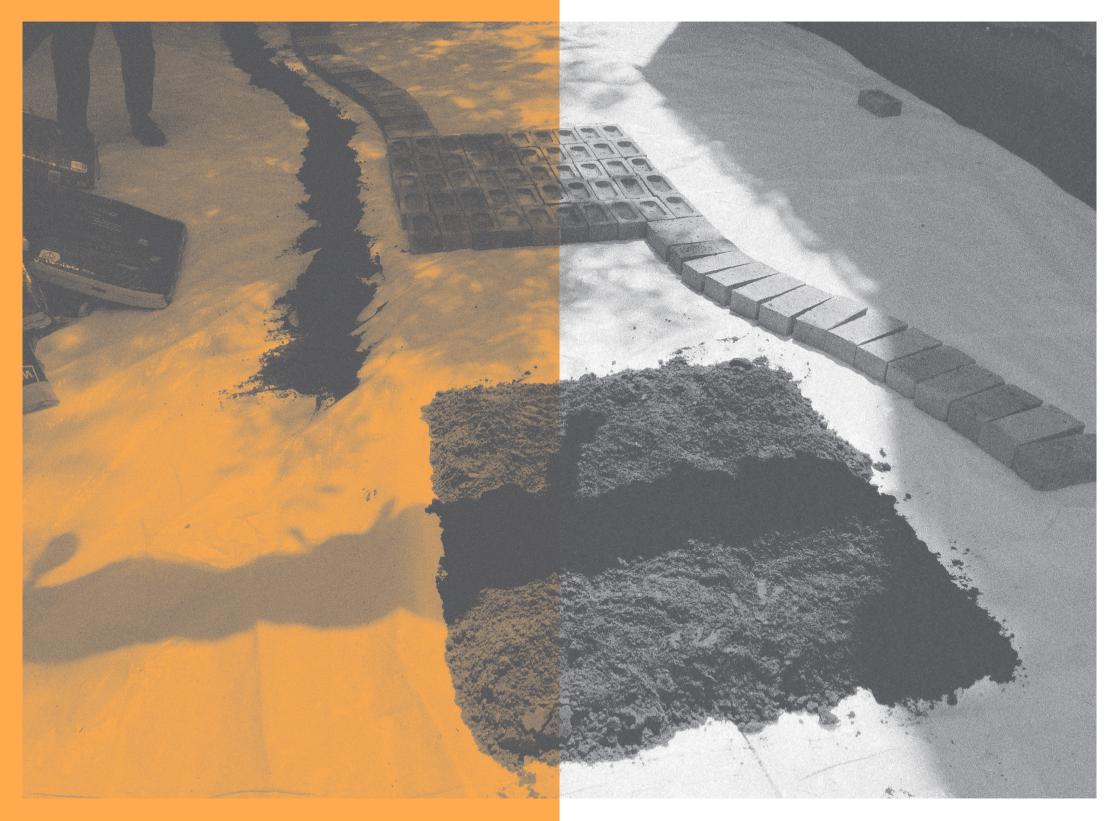
The Portman Early Childhood Centre and the preschools of Reggio Emilia show us that there are other possibilities; that all children have the right to an education that values relationships, creativity and care, and affirms and celebrates difference.

Busby, E., Parents Greenstein, A., seek legal action against government over 'national crisis' of special needs cuts, Independent, 26 September 2018, goo.gl/EbFkTP

Radical Inclusive Education, Concepts for Critical Psychology, Routledge, 2015,

Passed through the rails into the playground. Small hands receiving one by one. But they quickly built up and out and round and into something.

8





MIN NO Mark Str MILLER MOSSIN. SESSED. MINS

Utopian thought experiments built on bricks. Bricks of clay, like feet of clay, at risk of washing away. And maybe that's apt, that without due care and attention, the foundations, the very premise of what we're doing might be carried off.

When we think about education, how often do we think about it as a political act? While many of us simply take education for granted, it is in fact deeply political, underpinned by values that lead to the inclusion of some and the exclusion of others.

If we think about recent history, the politics of education becomes clear. Women, people of colour and disabled people have all had to fight their way in. It was not until 1920 that women were allowed to graduate from university. In South Africa, students were still segregated on the basis of colour until 1996, and until 1974 many disabled children were deemed 'ineducable'.

A key moment for a more inclusive approach to the education of disabled children came in the Warnock Report (1978), which introduced the term 'special educational needs'. Warnock stated that some 20 per cent of children would have 'special needs' at some point in their school career, and that these 'needs' should, wherever possible, be met in mainstream schools.

At the same time, disabled activists were coming together to campaign for equality and inclusion. In 1980, Mike Oliver, an activist and academic, published The Politics of Disablement. For the first time, Oliver proposed a social, rather than a medical, model of disability. Oliver used his social model to make a crucial distinction between what he described as 'impairment' and 'disablement'. Oliver, a person who uses a wheelchair, saw his impairment (his spinal cord injury), as distinct from his disablement (the exclusion he experienced in society). He argued that it was the disabling attitudes and structures in society that caused his disability, rather than disability being an inevitable consequence of his impairment.

Oliver's social model has become a very powerful tool for thinking about education. A social model shifts the focus away from thinking about an individual's 'problems' to thinking about what can be done to remove the barriers to their participation, for example, by building a ramp, fitting a hearing loop or providing a visual timetable. The work of Oliver, and many other disabled activists, underpinned the drafting of the Disability Discrimination Act (1995) and is still reflected in the Equality Act (2010) today. Social model thinking is at the heart of campaigns for inclusive education.

And yet, while the Equality Act talks about the 'rights' of disabled people, education policy and legislation still focuses on the 'special educational needs' of children (Children and

Runswick-Cole, K. and Hodge, N., Needs or rights? A challenge to the discourse of special education, British Journal of Special Education, 36 (4) (2009): 198–203.

Family Act, 2014). The language of education policy has yet to catch up with the language of the Equality Act – and this matters, simply because language matters. As an example, if I tell you that *I need* a chocolate biscuit, you can tell me I don't have a *right* to it and you can choose whether or not you give me the biscuit. Similarly, if we describe some children as having special educational *needs*, not *rights*, 1 then there is also a sense that meeting that need is optional. If we agree that non-disabled children have a right to their education then so should disabled children, regardless of whether or not some, or all, of that education is labelled as 'special'. Education is a right for all. Education is not a chocolate biscuit.



A curriculum that is focused on the development of children's literacy and numeracy skills through structured education excludes individuals who are not suited to learn through words and numbers. This problem holds especially true for young children who are perceived to have special educational needs and disabilities

Different materials allow children to learn in different ways. Valuing the diverse ways that individual children learn is a political act. An act that actively supports children's right to engage with the world in various ways. An act that draws attention to the importance of learning through the senses, including smell, taste, touch and sound. An act that celebrates the understanding that not all children are the same.

Bricks, sand, water, play dough, clay and wood all have the ability to open up unique cognitive, social, emotional and physical learning processes in children. Such materials also allow children to act in creative ways, forming new relationships with themselves, other people and the ever-changing world around them.

A three-year-old's play with a large, shiny blanket is not just a light-hearted activity. It is also a deeply educational one. As the blanket is thrown into the sky and drifts down over the child's body, the play encourages explorations of gravity, size, texture and space through movement, throwing, catching and touch. At the same time, the shiny blanket gives the child agency to transform and interact with the spaces that surround them as well as in a way that aligns with their unique curiosities and abilities.

Children's play with materials is critical in early childhood education as it allows them to imagine, act and feel in alternate ways. Children tell stories as they play with materials. They create new narratives and new ways of thinking that allow for the imagination of new possible futures.

Many early childhood educators are aware of the importance of children's multisensory learning with materials. Every day they diligently set up play tables, sensory boxes and outdoor play equipment in preparation for children to have learning experiences with materials at preschool. But how does an early years framework focused on preparing children for 'school readiness' support the diverse and unique ways that individuals learn? And what effect does this have on the children who do not fit the mould of mainstream education?

What is a nursery after all? A place of nurturing, of tending. Just as a gardener gives each seedling the best possible conditions, the right soil type, the correct temperature and the right amount of water to flourish, so all the children, in their nursery, need the right care for them. And just as a tomato plant makes a bad daffodil, and vice versa, no two children are the same, don't require the same, and should never be judged or measured in terms of how well they are someone else.

The collaboration between the Serpentine, the Portman Early Childhood Centre, Emma McGarry and Adam J B Walker investigates the political, ethical and power structures that shape the experiences of children and families with special needs and disabilities in early childhood education.

This publication questions the inclusionary and exclusionary educational policies and practices that directly affect these individuals' lives, and it calls for a shift in thinking from a focus on children's needs towards advocating for children's right to an educational system that actively fosters difference. Material-rich environments, and children's play within them, have a critical role in producing children's opportunities to learn and experience the world in different ways.

At its core, this collaboration also celebrates the diverse ways in which children with special needs and disabilities learn and the important contribution this makes to the development of democratic communities



'It took me two years to become pregnant; I tried and tried for two long years. I was so happy when I found out I was pregnant and going to be a mum. I thought, at first, she was going to be a boy. Until I had a scan and then I just knew she was a girl. When I became six months pregnant I was so excited to buy things, clothes, a pram from Mamas and Papas and all the things she would need. I loved swimming and being in water when I was pregnant, I think Dina got that from me. She is my little mermaid.

Towards the end of my pregnancy, I was starting to get worried; I didn't feel her in my tummy for two days. Thankfully, Dina was born healthy, she weighed 3.5 kilos and was 55 cm. When she was born she was like a chicken, all tiny, when I held her. I was so sensitive to her, I felt pure love... I loved her so much. I cried the whole night the first night I held her because I felt so connected to her.

When Dina was three I found out she was autistic. I was heartbroken. I didn't know what autism meant and I didn't know anyone who had a child with autism. I was very down and I forgot about myself. I didn't feel like I was in the world... I felt judged by everyone. Sometimes, with people in my community, I felt like they would avoid me – it was like they didn't know what to say to me or were afraid of Dina. Ultimately, I felt blamed for Dina's autism, some people even said that because I wasn't a good mum Dina was autistic. That's how little some people know about autism. It was a very difficult time for me and I cried a lot.



Eventually, I came to drop-in and nursery... I was so scared, I didn't know what to expect. At first, I was sceptical, I thought they were going to tell me she was too difficult and that they didn't want us to come anymore. But everyone was really welcoming to me and I realised that all children were welcome. I'd had a really bad experience of nursery before – they would hide toys away because Dina would tip things out of the baskets. They would always tell me her behaviour was "too much!"

I was able to meet other parents in a similar situation to me and make friends. The coffee mornings also really helped because I could talk to people and they got it. For a long time my family didn't understand me, I'd waited so long to be understood and that's what I got. The coffee mornings gave me a new community that understood me. Like I say, I was very down when I began my journey, but the longer I came the more I started to recognise myself again. I started to take care of myself as well as Dina because I started to feel like it wasn't the end of the world. Dina still has her moments and I am not saying my journey has become easy! There are days when I am frustrated or overwhelmed, but everyone helps me when I am down. Everyone knows me and Dina... all the staff offer help when I need it.

It was later, meeting with the parents at the coffee morning, that someone said it: 'I would like to see each nursery or play centre welcoming our children with special needs in the same way that other children are welcomed.'

Adom loves songs and so I try to make up songs with words that he likes. Before introducing a new activity, we do some singing first to get him focussed.

The nursery taught me how to let Dina play. I used to be so worried about mess and her clothes. But the nursery reassured me and showed me what Dina was learning through play. They made me feel relaxed because I didn't panic about her tipping things out or wanting to paint or get messy. I feel part of the team, they work alongside me and never judge me. I've learned Dina's behaviour always has a reason. You have to be like a detective. We have our own communication and I can interpret the things she shows me and takes my hand to.

Dina has changed a lot since she first started. She used to try and climb all over things... on the windows! Now she is calmer and she is becoming more independent and standing on her own feet. She is trying to say words and understands more and more every day. I've learned to become tough and fight for what Dina needs and deserves. She is my child and I will never give up. I am very proud of Dina and me!'

27



'When I arrived at the nursery my son was already there with his dad and had taken his shoes off. That was a good sign as he only did that when he felt at home (comfortable). They had also provided him with a wooden toy of doors for him to open and shut as he liked doing that then. Everyone was friendly.

I remember Amal was with him on our first visit and she seemed to know what she was doing and looked happy doing it. It didn't feel like my son was "bothering" her moving back and forth to the toilets. We decided maybe we can give Portman a try.

When I hear other parents, from other nurseries, complain that the teachers mostly tell them of the "bad" things their children did during the day, here they always look for solutions to solve the "problem" working with parents all the way.

For some reason my local authority wanted my son to go to a local mainstream school even though he clearly wouldn't have been able to cope. Setting my son up to fail did not concern my local authority. But Portman was concerned and supported us all the way through to getting a school that is well suited for him.

Do not accept anything but the best for your child. You know your child and what they can and cannot do, so do not let somebody who does not know your child tell you where to take them.'



'Little did I know that at the age of two years my son Ismael spoke less than twenty words. He mostly pointed at objects he wanted and we would rush to get him whatever he needed. He held toys with two fingers instead of having a firm grip with all five fingers. Ismael did not really play with other children his age. On our trips to playgrounds, usually we would find him just wandering around within the playground and playing on his own. As Ismael's mother I felt that he needed to maybe be around other children so he could improve his social skills. I registered him at nursery.

Once Ismael started that first nursery I'd leave him for two and a half hours. When I would come back to pick him up and ask how his morning was, all I'd get from staff members was that he was all right and see you tomorrow. The next few days I kind of hoped they would communicate more as I had expressed my concerns, especially seeing other children his age speak so well and play pretend games; whereas my son would just wander around from table to table. I still didn't get more feedback other than he was alright and he doesn't really focus on one particular toy he's playing with. After eight days, I stopped taking Ismael to that first nursery. I felt so disheartened and not at all comfortable around the staff because the only time I was ever approached by a staff member was when they needed the top-up money for material he was going to use (costing £5 a day).

Re-emerging into the sunlight it was different. The nursery was the same, but also not the same. Something in the way people acknowledged one another, welcomed each child, took time to listen, to try to understand. It shouldn't have felt unusual.

As more of us emerged through the portal, someone dared to ask: here, in this place of possible reality, would we all be accepted, as we were in our differences and complexities? Particularly we were thinking of those with what were sometimes termed 'special needs' back on our side of the wormhole.



I went to see a health visitor for Ismael's two-vear child development check. That's when the health visitor asked, how many words does Ismael speak? When I said he doesn't really speak at all - only "mum" and "dada" - they then asked me "does he attend the Portman Early Childhood Centre?" I said no I'd never heard of it. They advised me to take Ismael to the drop-in and reassured me that the staff are actually really helpful compared to what my negative experience was. The health visitor also urged me to visit my GP and inform them that my son was speaking less than twenty words - he would be referred to a speech therapist. Knowing now that the Portman exists, I Googled the address and what the drop-in times were and decided to follow the advice of the health visitor.

Once I came to the drop-in, I was immediately met by a staff member on the first floor. She registered my son and myself and advised me on all the activities Ismael could be doing. I noticed immediately that the children were so calm and peaceful with staff members and their parents. Ismael also started, at that time, having very bad tantrums and staff members actually came to tell me that it was normal and what I should be doing to slowly get him out of it. At first I was very awkward and blamed myself a lot for his behaviour. Many times when I felt like just going back home and hiding away a staff member would come and reassure me that he was at the best place and that he would grow out of the tantrums but consistency was the key. I learned so many things at Portman that I don't think I would

have ever known. Portman helped me to become more at ease with being a parent and to stop punishing myself when things didn't go well with my son.

The staff made me feel at home with Ismael, and when he started full-time nursery at the age of three I was still able to come back for advice regarding my son's progress with Amie and a parenting practitioner. I was put on a triple-P parenting course, which enabled me to look at my own parenting style and adapt the key points learned and actually apply it whenever Ismael had a tantrum. Also, as soon after I finished the course, I could take Ismael on trips and go shopping without having to worry about his behaviour. I learned to plan ahead and communicate effectively without raising my voice. At this stage Ismael was aged four and had been diagnosed with a global developmental delay of one year, and required more speech therapy.

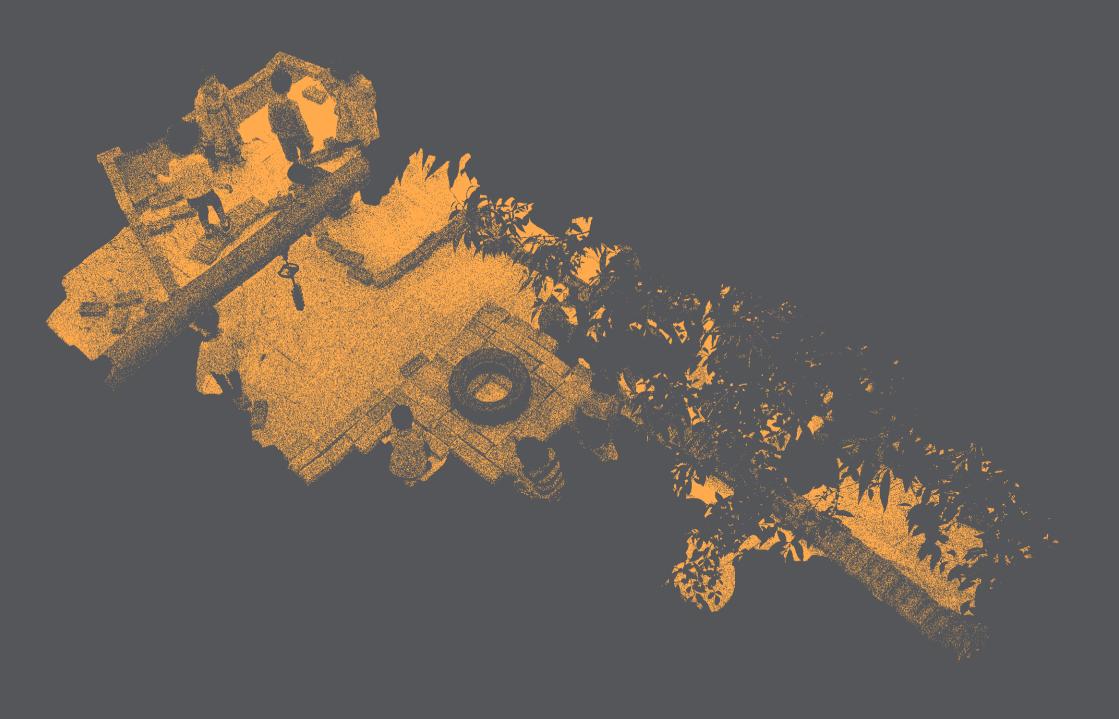
Amie taught me that no child is the same, that it's OK for a child to do things at their own pace and that we need to stimulate their growth with understanding and compassion instead of pushing them into something they are not yet ready for. Amie also enabled me to attend the coffee mornings once a month with other parents whose children have special needs. I've learned to look beyond my own situation and see that there are other parents with similar stories, provide support to fellow mums and possibly fight for better support from local services and schools (especially those that say they are inclusive).'

The answer came without hesitation: 'Yes, of course. They have first priority for admission. We consider them to be children with special rights!'. And with paradoxical relief that's when we realised we weren't in a utopia after all. A true utopia wouldn't require rights because equality could be universally presumed. We weren't disappointed though: in fact the opposite.

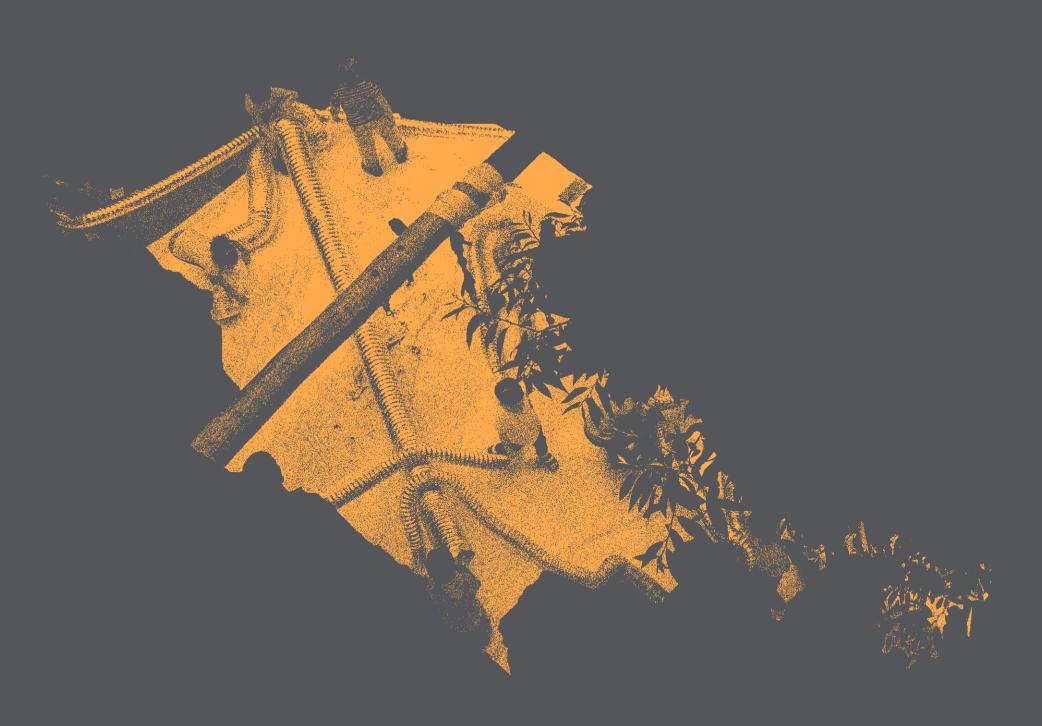
## THINGS THAT NEED TO CHANGE (or TO CREATE MY IDEAL NURSERY...)

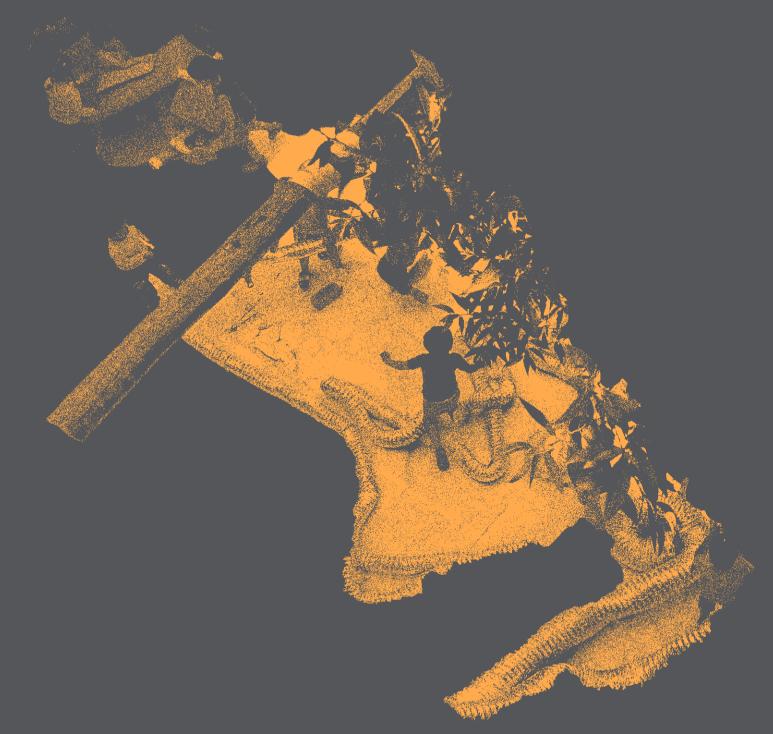
- 1. Learn my name.
- 2. Don't make assumptions about my child, ask me.
- 3. Let me come into the room.
- 4. Don't just listen, you need to hear me.
- 5. Don't ignore my child.
- 6. Don't assume my child is naughty, ask me to know more.
- 7. Stop wanting perfection.
- 8. Please understand, if my child hasn't slept they won't have a good day.
- 9. Be patient.
- 10. Make time for me to help you understand my child.
- 11. Be less judgemental.
- 12. Don't make me feel like a criminal.
- 13. Ask me what is important to my child, ask me what is important to me.
- 14. Don't expect me to fix what happened at nursery.
- 15. Work with parents, don't blame them.
- 16. Learn more about learning differences.
- 17. Trust me.
- 18. Support me.



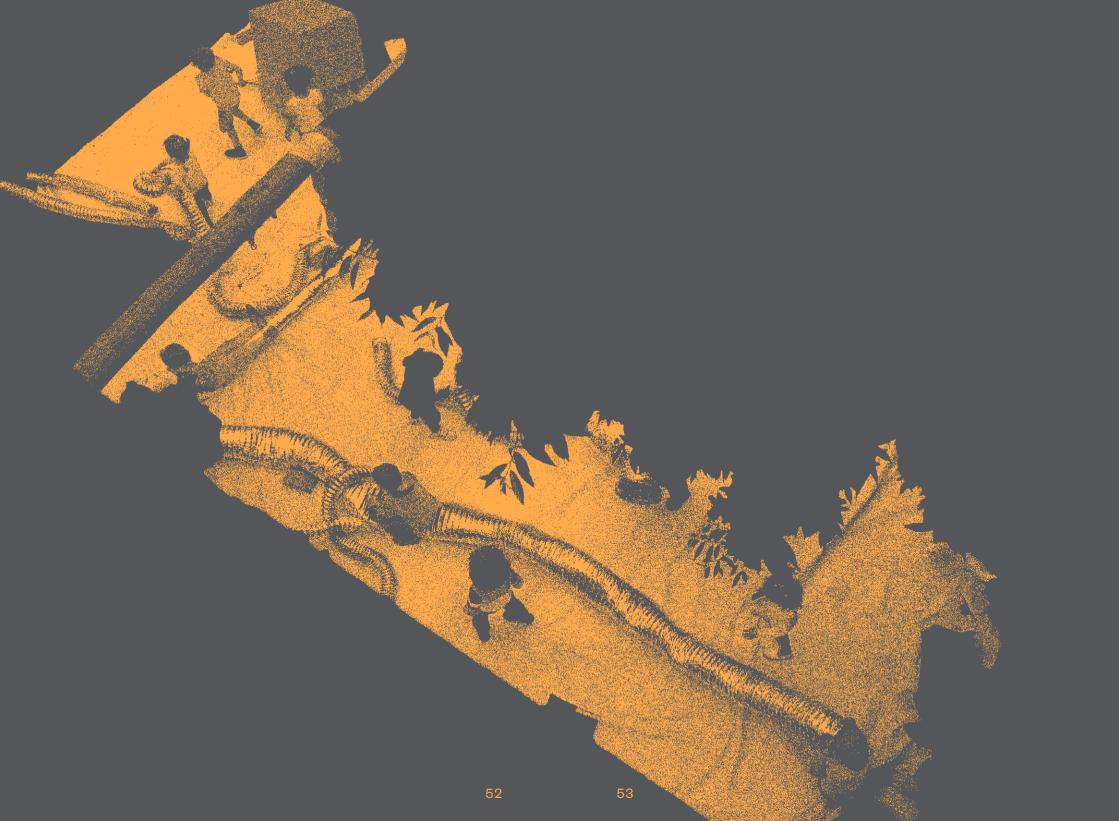












- 1. Go to nursery.
- 2. Go to school.
- 3. Be respected for, and in, their own differences.
- 4. Be treated as an individual.
- 5. Be who they need to be.
- 6. Be loved.
- 7. Be happy.
- 8. Be silly.
- 9. Be cared for.
- 10. Be wanted.
- 11. Be heard.
- 12. Be understood.
- 13. Be safe.
- 14. Feel safe.
- 15. Make mistakes.
- 16. Show emotion.
- 17. Have an opinion.
- 18. Learn.
- 19. Learn in their own way at their own pace.
- 20. Be their present self, and be supported to become their future self.
- 21. Be supported by adults that have open minds and big hearts.
- 22. Get the support they need today for a better tomorrow.

We'd known as soon as we came through to this place we had to go back to our reality and we knew we couldn't take real utopian equality back through with us. It was too alien to the world we knew. But rights! Rights were manageable, achievable perhaps. And could make a difference



'My name is Kidus and I am fourteen years old. I'm now in year ten and three years ago I was told that I had Asperger's syndrome and ADHD. I was vounger and didn't really understand what it was and how exactly it was going to change my life. When some of my teachers heard, instead of helping me fit in. life for me was made much, much harder. No matter what I did, how hard I tried, for three years nothing changed for the better. Therefore, I figured instead of relying on the teachers for help I would take matters into my own hands. I showed the teachers that with the help of my lovely and supporting family, I could study hard, have fun and show that autism isn't just some disability but that I wouldn't be me without it. That is my story. How was I able to fit in? I started conversations which escalated into longterm friendships. Autism has had multiple effects on me, some being positive (like being smart, fun and energetic), some being negative (like focus and concentration problems). But everyone has their ups and downs and as long as you try your hardest, whether you are autistic or not, you can achieve almost anything!'

They help me get all the ingredients ready: chopping, dicing, gathering pots and pans. We make it our own little cooking show.

'My name is Emmanuel and I have two autistic brothers. One who is older than me named Kidus and the vounger one who's called Jacob. They are both hard to handle or even have fun with because Kidus and Jacob get angry if they don't get what they want. Jacob (who I share a room with) makes it harder for me to sleep because he'll keep the lights on because he is scared of the dark. I have to wait until he sleeps before I switch off the lights. This is not easy because due to Jacob being autistic he is energetic and doesn't sleep quickly. Kidus also makes it hard to sleep because he'll keep coming into my room and distracting me by speaking a lot about his favourite stuff. After this I know most people might be thinking that autistic people are bad but they really aren't. They just can't help it, it's not because they are evil they just can't help it. So I need people to do me a big favour and help those who are autistic. I wish for those people who know someone who is autistic to do something to help because they are struggling when they go to school. They get bullied for being weird because they can't figure out what is going on. They need people to stop that; teachers can't because they don't understand what is happening. Teachers don't know because they aren't taught. People need to go to an autistic person and help them. Thank you.'



'I suppose for me and for my son it comes back to communication and the type of communication. I'd get called in at the end of the day or I'd get a phone call to go and have a meeting about the negative behaviour that he was showing, and if I ever asked about his behaviour when they didn't call me over, oh yeah, he's fine, but I wouldn't actually get the details. I would never be told the really good things that he'd done. And even down to parents' evenings I'd be told, oh, your son's a beautiful boy but he does this, but then if I asked about other aspects of the curriculum, oh yeah, he's meeting this and he's meeting that and he's meeting that. But I actually had to ask to hear the positive, but they were very quick to share the negative with people.

So it's a very them-centred way of thinking through your child being in nursery.'

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'For my son, when he was in nursery, I was always called up; always told at the end of the day that he wasn't sitting down, he wasn't listening, he wasn't behaving, he wasn't showing eye contact. To me, it felt like "I bring my child here for you to help him understand those things". But I always felt like "what am I doing wrong?" So I would end up being frustrated, with him too, reinforcing the whole thing, which frustrates the child even more.

I felt like what I was doing was punishing him literally just for going to nursery, which wasn't the right way to go about it. It came to a point where he would be at home with me and he would be fine, but at school I would go and I would hear "he did this, he did that". At the time he wasn't talking as much as other children, and I felt at some point he was getting a lot of the blame as well because he couldn't speak back.

I think as a parent if you just go by what the teacher tells you, sometimes that can be dangerous. They weren't stimulating him enough, and if he was doing certain things it's because he wasn't getting that attention he needed, especially for a child who's got speech delay. I thought, why was nobody sitting me down and telling me he's got speech delay, maybe you could do this, this and this? And we could do that, so we can come together and make it a more enjoyable experience for him.'

The visits there aren't without their sadness

'I felt I failed him a lot in the first year of his nursery. Then when we got to reception they kept telling me that something was not right with him. Again, I felt he was still being punished on the basis of his history in the school. And when I found out he had a speech delay and a global developmental delay of a year I just sat down and said: "Listen, I can't do this anymore. We need to work together. I can't constantly come to the school for you guys to tell me something's wrong and he's not progressing. He's just coming back more frustrated all the time and telling me he's not good enough. I'm not good enough." I can't do that.

So luckily now, he's in year one and they finally realised that they were doing something wrong as well, and they've got someone actually sitting down with him and boosting his confidence, talking to him more. Instead of telling him off, sitting down and trying to understand what's going on with him.

I've actually noticed now he's a more positive child. He's more talkative, he's more eager to learn. If they did this in reception or nursery all of this could have been prevented. There's a lack of understanding that children are different, and they just want all the children to be the same, and sorry, but you can't do that.'

We have a place where he can go and be angry, or calm down, with a bean bag and soft pillows. I give him time, let him be angry. And I praise him and keep telling him that I love him.

It's wonderful of course, being in this parallel dimension or other planet or whatever this place is. But we always know we have to return back through the tunnels.



'When I was trying to find a nursery I applied to quite a few and I was looking for "outstanding". I ended up getting a few places around my area, so I was happy, and then I saw what it was like. When I took him they asked me, "Oh why is your son still not speaking?" When I explained he had a developmental delay, maybe autism, their response was "okay, what are you feeding him?"!

I asked them if they had any experience with children with autism or special needs? They replied, "No, not really." And I asked if they had staff who could support my son, because I thought, although he wasn't yet diagnosed, that he might have autism. The response was, "Maybe? You could apply for this...?" So that's what they said. I felt like as soon as they knew that he might have that condition they didn't want to take him.

"He can stay or he can leave, take it or leave it." It was that kind of situation. And they're "outstanding"! Ofsted really needs to revise the criteria for a nursery to achieve outstanding. Recent research shows that one in fifty-nine children is affected by autism, and if they're really not supporting those children, how on earth could they get outstanding? This really upsets me.

And it's not only one nursery, it was similar at quite a few of the nurseries I went to. I found somewhere eventually, but now I have to travel quite a distance to bring in my son every day for just two and a half hours. If they really recognised that children

especially need the same rights, they have the same rights, I wouldn't have to travel all the time to get the right support. That really upsets me: "Why are they getting outstanding and then...?"

Many nurseries don't have a sensory room. They don't have anything. If you have a child with specific needs you, as a parent, have to try to find the right place for them to be stimulated otherwise they will be left behind. It's really sad that's happening.'

We have a visual timetable so he understands which days there are after school clubs, and which days I will pick him up. At the weekend, when each day is different, we have another visual timetable to tell him what will happen, as he struggles with unpredictable days.

Both lights at the end of the tunnel matter.

'At my son's school he had an educational psychologist come in, because they have the points scoring system where the child gets points if they paid attention, if they've done their work they get points, and it's very hard for a child who's a bit behind and who's still picking up on a lot of things, so my son used to end up frustrated because he would see his friends get ten points, twenty points, and at the end of the day he would look at his little icon thingy and he's still at five points where everybody else is at thirty or forty points. They never seemed to understand. And I kept telling them because you have unrealistic expectations of them. He is not the same like all the other children. He is good in his own way. Why don't you find things that he does and reward them as good? But when the educational psychologist came and he listened to all three teachers talk about him he was just laughing his head off. He said, can she not see what you guys do? Why is he crying? He's crying because you're shutting him up. You're telling him be as good as that or just don't, just get out of the classroom, and he will be pulled from his classroom to the head's office and he will be sitting there all day.

But then we want young adults to do things like having an opinion and voting, but then right from very early on you're asked not to have an opinion, not to speak out, to comply, and this is what you're being taught right from when you're three, two now with the two-year offer.

— Yeah, that's what the teachers did not seem to realise. You're not teaching him anything, you're just telling him we don't want him... stop.



But learning should be fun, and so...

— Yeah, but it's not fun. It's frustrating for them.

And so by the time they've been three years into school they've given up, and you've got so much education left.'



But the other too, because it's really hard and that needs to be acknowledged. The stories we heard, from parents, recount the reality. In Westminster. In 2018.

'The only way it changed was because of you as a parent making it change rather than anyone else realising. It's not fair. And I spoke to other mums in the classroom and they were like yeah, we've noticed the same thing. I said, then why are we accepting it?

I think you guys should speak up then.

— I did. I went to the SFNCO.

No, all of you talk, say this is not normal.

— Yeah. No, we wrote a letter and signed it.

Or say or we're going to move. The whole school is going to be empty.

— They stopped it because I said it's not fair. They're only like five and six. If you're going to start doing this what do you expect for them educationwise or building friendships? It's like continuously I'm not good enough or they don't want this or they don't want that. It's like he's not going to want to go to school or be among other people.

It's not nice for them as well.

— But what happened to inspiring learning to encourage curiosity, to ask questions, to challenge? All these things that are fundamental to higher learning.

But why is a school like this now then, Amie? I feel like they don't want this... like get the money and go.

— I mean, teachers are under a lot of pressure. They are under a lot of pressure.

Of course, I understand, but...

— Because the way the school system is moving, the curriculum is largely based on fact finding. You've got to find your facts and you've all got to do it in this way and you've got to write this way. And even time in schools, they have to fit so much in for the curriculum to meet school standards. They have thirty minutes of literacy, thirty minutes of numeracy. Oh, we'll skip PE because... And PE is so important. To be able to write you need to be able to have well-developed physical skills, but these are the foundations you're taught in early years that to be a writer...'

My son loves playing with lego and building things. He loves books with pictures and memorising the names of things. He loves nursery rhymes and we sing together. Sometimes (most times), when he wants to play I leave what I am doing and I play with him.



'My name is Gigi and I have four children: Kidus (14), Emmanuel (12), Ruth (9) and Jacob (7). My journey started at Portman just after I had given birth to my first child, Kidus. Portman is like the other half of my body (every piece of me). The material, the sofa, the noise, the table: it's half of my life... It reminds me of everything in my life.

The first day I came to Portman Kidus was four months old. When I had Kidus, he wouldn't stop crying, vomiting he was so restless. I didn't understand what was going on – he was my first child and I didn't know if this was normal or not. I didn't understand what people were telling me as I didn't have any English. I became so down, I thought people were going to take my baby. I would close the curtains, the doors, I just stopped talking to people. I had post-natal depression and I couldn't understand why my baby didn't sleep, wouldn't eat – he was so restless all the time.

I had a midwife, Jane, and she came to my house every day to see me. Every day she would come and tell me to go to Portman. She would always ask me, "just let me show you around the place". Every day she would come with an interpreter and encourage me to go and visit. Finally, I relented and decided to go and take a look. Jane took me to Portman and showed me around and from that day my heart has stayed there. Even though on the first day I was shaking and sweating... I was so scared.



Those tubes were engaging. Essentially they were a coiled wire over which foil was affixed. Amidst the crawling through, throwing things down, and pulling taught, a few children enjoyed picking at an end of a tube, pulling the wire out, unravelling it.

When I got to Portman I was so shocked, nobody stared at me or judged me. The staff didn't care that Kidus was screaming, one of the teachers took him and held him. It was the first time a stranger had held my baby but I didn't feel like they were a stranger. For the first time I felt like my head had stopped spinning and my mind was able to be still. I instantly relaxed.

From that day on, I took Kidus to Portman every day for five days a week. He would always calm down in the sensory room. The people were so kind and helpful. It was like people were holding me with two hands after I had felt lost for so long.

Portman means so much to me, even my kids know where to go for help. If something happened to me I know my kids would go straight there for help. I remember going in one day and being so down... I hadn't slept or eaten. I remember the head teacher, Jo, telling another teacher to take my pushchair so that I could go and sleep in the basement. I slept the whole day... I was so exhausted. I've always come to Portman for help and I have learned a lot of things as well. My head is so much better now and I never gave up. I became strong, I went to college and passed my exams and I learned English.

My youngest, Jacob, was born in amongst this; he also came to Portman. He had a great time there. When it was time for Jacob to go to big school this didn't go well for him either. He stopped talking for a whole year and was diagnosed in March 2015 with

Keep on unpicking.

Keep on unpicking.

Keep on unpicking.

autism. Similarly to Kidus, Jacob doesn't sleep and finds it difficult to sit still or concentrate. The last three years have been really painful since Kidus has been at secondary and Jacob was diagnosed.

Looking back a lot of things have been hard but I have learned about everything I can do for my children because of Portman. At Portman my children are accepted, they are loved, they have family, they count as people and they are treated normally. I don't have enough words to describe how I feel. I have passed a lot of tests in my life and if it wasn't for Portman I don't know how I would have got through it.

Now my four special, incredible, beautiful children have been a true gift from God. I wish I could take their worry and pain away. I try every day to be the kind of parent they deserve and I hope I am as much of a gift to them as they are to me. They are the light of my life, they are my hope and my reason to live. My hope is that one day my children will live in a world where they will be accepted, happy, appreciated and successful with their differences. As long as I am here, I try to surround them with people who love and accept them as they are and help them navigate this life because autism never takes a day off!'



'I had noticed things were not right when my son Z was eighteen months old and I started to seek help from there on. We had to wait for about a year for his diagnosis and during this time, I couldn't help it, I got so stressed that this crucial time of his brain development was passing without the early intervention. I had to stop working and try to help him as much as I could by taking him to drop-in, parks, etc.

Finding the right nursery was not an easy one; I remember visiting most of the nurseries in my area and coming home feeling down, thinking my son would be left behind.

After the diagnosis, I thought that from now on things will flow and Z will get all the help he needs to thrive. But unfortunately that was not the case. I even had to chase for his diagnosis report to be sent out to his nursery and me after more than a month of waiting. Trying to get the needed therapy appointments is still an ongoing battle – an average waiting time of nine months!

I am at the beginning of a journey, which I dread the most! Hearing from parents about their older children with SEND caught in a battle... stories about mainstream schools, makes me worry even more about the future.'

And the structure between both sides of the portal might, just might, eventually dissolve, bringing together that which is with how it could be.

For Yasser, I play football at home which helps. I don't put pressure on him when he is finding it difficult to tell me what he is angry or upset about.



# Exclusion

## Where is the individual child in the

In the context of national outcomes at the age of five, as reported through the early years foundation stage profile 'disadvantaged children' refers to those who are known to be eligible for free school meals.

'Early years (under-Ss) foundation stage framework (EYFS)', Department for Education, March 2014;

Bold beginnings - November 2017, No. 170045

Years). December 2017. Read full response at tactyc.org.uk.

Many parents I have met in my role speak of feeling a sense of loss and grief when their child is diagnosed. It didn't matter how many times they had acknowledged their child's difficulties before - 'diagnosis day' made it real. Having had to wait so long for a diagnosis, parents always had an expectation that when they got it support networks and services would flood in. However, in reality many parents describe being hit with diagnosis and then nothing... apart from an overwhelming sense of isolation and loneliness.

From this sense of 'nothingness' we identified a real need in school communities to have a space for parents who have children with special educational needs and disabilities (SEND). We wanted to create a safe forum where parents could get to know each other and have an opportunity to share experiences. This led to us setting up coffee mornings for parents. which are relaxed, informal and most importantly a space without judgement.

Our model of coffee mornings are unstructured and without any agenda. We encourage discussions to grow organically so that we can be responsive to parents' needs. We acknowledge the views of parents, we listen... but most importantly we hear them. We have learned from parents attending coffee mornings that sometimes just being asked 'are you OK?' is enough. Knowing there is a network of support for parents gives them the opportunity to draw on their own inner strength and the strength of others to continue to move forward in their journeys. Equally, there is real value in being with others that understand, as every parent is at a different stage of the process.

Through the coffee mornings, we have been able to support parents to feel empowered to advocate for their children. Together, we learn key information around SEND and support parents in navigating their way through difficult systems, referral routes and professional 'iargon'. Often parents speak of this as being a barrier to accessing wider services. Similarly, we invite a range of professionals to attend our coffee mornings to talk about their services. This assists parents in making informed decisions about their children. We also encourage parents to recognise the importance of learning in the home and their capacity as their child's educators.

Ultimately, our coffee mornings give the message to parents that we care, we hear you, we understand, we support you and you are not on your own.

We give parents permission to be angry, sad, frustrated and to cry; to laugh, shout and celebrate.

#### PLACES OF SUPPORT

A list of local and national organisations who provide information and support, and campaign for change.

The Alliance for Inclusive Education campaigns for the right of all Disabled pupils and students to be fully included in mainstream education, training and apprenticeships.

·allfie.org.uk

Contact supports families with guidance and information. They bring families together to support each other and help them to campaign, volunteer and fundraise to improve life for themselves and others.

· contact.org.uk

The Council for Disabled Children is the umbrella body for the disabled children's sector bringing together professionals, practitioners and policy-makers. They have an extensive list of members.

· councilfordisabledchildren.org.uk > Meet-our-members

The Disability Living Allowance (DLA) for Children website contains information about available help with the extra costs of looking after a child with disabilities.

· gov.uk/disability-living -allowance-children

The Down's Syndrome Association offers information, support and advice on any question or concern related to Down's syndrome. They have specialist advisers who can provide information and support on issues such as health, social care, benefits and education for people with Down's syndrome.

·downs-syndrome.org.uk

The Educational Rights Alliance is a national, grassroots organisation committed to advancing equality in education for children and young people with disabilities. They campaign for children and young people with SEN to be seen as having educational rights not 'special needs', and promote equality rather than inclusion in schools and local authorities.

educationalrightsalliance.blogspot.com

Independent Parental
Special Education Advice (known as IPSEA) offers free and independent legally based information, advice and support to help get the right education for children and young people with SEND. They also provide training on the SEND legal framework to parents and carers, professionals and other organisations.

ipsea.org.uk

Hackney Special Education Crisis works with parent and carer groups around the country to raise funds for a judicial review against the Secretary of State for Education concerning underfunding of SEND provision throughout the UK.

·hackneyspecialeducationcrisis.co.uk

Kids is a national charity, providing a wide range of support services to disabled children, young people and their families. They offer support to the whole family with the aim of giving disabled children a brighter future.

·kids.org.uk

Mumsnet is a website where parents can swap advice about all the stuff parents talk about. Their aim is to make parents' lives easier by pooling knowledge, advice and support.

· mumsnet.com

The National Autistic Society is the UK's largest provider of specialist autism services for autistic people, parents and carers, and professionals.

autism.org.uk

Scope is a disability equality charity. Their aim is to achieve a society where all disabled people enjoy equality and fairness. They provide practical advice and emotional support whenever people need it most.

·scope.org.uk

Special Needs Jungle is an organisation run by parents providing support and information about all aspects of SEN and disability in the UK. The website contains useful information about SEN and disability issues faced by children and their parents.

specialneedsjungle.com

Westminster City Council's Local Offer for Special Educational Needs and Disabilities provides information about services that children, young people and their families can expect from a range of local agencies.

• <u>fisd.westminster.gov.uk</u> > information for families > SEND local offer

The Westminster Information Advice Support Service for SEND offers a free confidential service available to parents, children and young people who live in the three boroughs. They can help by providing access to impartial guidance and support on matters relating to the law, local policy and practice, the local offer and Education, Health and Care (EHC) assessments.

westminsteriass.co.uk

The Westminster Parents
Participation Group is a parent-led
group for all Westminster parents
and carers of children and adults
with SEN and/or a disability. They
have regular drop-in sessions where
parents can meet together, ask
questions, talk and feel listened to.

·wppg.org.uk

The Westminster Society
is a charity providing services for
people with a range of learning
disabilities and their families. They
operate in Westminster and other
London boroughs supporting
people with disabilities, including
people with complex needs and
profound and multiple disabilities.

wspld.org.uk

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serpentinegalleries.org/learn

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### SERPE NTINE GALLERIES

- 10. MAKE TIME FOR ME
  TO HELP YOU
  UNDERSTAND MY CHILD
- 11. BE LESS JUDGEMENTAL
- 12. DON'T MAKE ME FEEL LIKE A CRIMINAL
- 13. ASK ME WHAT IS
  IMPORTANT TO MY
  CHILD; ASK ME
  WHAT IS IMPORTANT
  TO ME
- 14. DON'T EXPECT ME
  TO FIX WHAT
  HAPPENED
  AT NURSERY
- 15. WORK WITH PARENTS, DON'T BLAME THEM
- 16. LEARN MORE
  ABOUT LEARNING
  DIFFERENCES
  TRUIST ME
- 17. TRUST ME
- 18. SUPPORT ME

- 19. LEARN IN THEIR
  OWN WAY AT
  THEIR OWN PACE
- 20. BE THEIR PRESENT SELF, AND BE SUPPORTED TO BECOME THEIR FUTURE SELF
- BE SUPPORTED
  BY ADULTS THAT
  HAVE OPEN MINDS
  AND BIG HEARTS
- 22. GET THE SUPPORT THEY NEED TODAY FOR A BETTER TOMORROW