



Embracing Complexity

**Towards New Approaches
for Supporting People with
Neurodevelopmental
Conditions**



This report was first published in May 2019.
For enquiries, please contact info@autistica.org.uk

Language choices: In the survey and report and in consultation with the charities' experts by experience, we have used the term "people with neurodevelopmental conditions/people with NDCs". There is no research on preferred language across this very large and diverse group of people and we acknowledge that this language may not be preferred by everyone represented in the report.

Acknowledgements

We would like to thank all of the charities who helped conduct this survey, with special thanks to the steering committee of charities who inputted into the writing of this report - ADHD Foundation, Afacic, Down Syndrome Research Foundation UK, Epilepsy Action, McPin Foundation, MQ, The Neurological Alliance and Tourettes Action - led by Autistica, the UK's national autism research charity.

We would also like to thank JPA Health Communications who generously supported the writing of the report as a donation to the cause.

Finally, our greatest thanks go to all the people who completed the questionnaire for sharing their insight and deeply personal experiences of living with neurodevelopmental conditions so that together we can better tackle the unmet needs of the wider community.

The Embracing Complexity Coalition



embracingcomplexity.org.uk

Recommendations



01 Diagnosis

People with neurodevelopmental conditions (NDCs) are waiting too long for initial diagnosis. Furthermore, health services do not adequately recognise or plan for the high likelihood of multiple neurodevelopmental diagnoses. Diagnostic pathways should take account of high levels of multimorbidity and waiting times should be time limited and monitored.

“ **Navigating the system to find health professionals capable of assessing neurodevelopment problems and disorders has been difficult. Accessing the right support and joining up education and health has been challenging. Finding the right education setting and getting support agreed through the local authority has been a minefield. We’ve got there but the emotional toll on parents/carers is long-term and huge.** ”

02 Support



Despite often high levels of need, people with neurodevelopmental conditions and their families are too often inadequately supported in many areas of their lives. At diagnosis, people should be informed about what their diagnosis is likely to mean for them and which other conditions or challenges they might experience. Public services of all kinds should take greater account of the needs of people with NDCs through better training, reasonable adjustments and proactive supports.



03 Research

We understand far too little about neurodevelopmental conditions, the lived experience of people with these conditions and the best ways to improve outcomes. Greater investment is urgently needed in research into neurodevelopmental conditions (individually and collectively), informed by the priorities of people with NDCs. Research funders should seek to increase their impact by identifying opportunities to tackle challenges which cross diagnostic boundaries. Further research to understand the true overlap between conditions and the common challenges faced by people with neurodevelopmental conditions should be undertaken, both to improve outcomes and to suggest new ways to deliver more joined-up diagnosis and services.

“ **I worry about the future.** ”

“ **Society is NOT inclusive, and a real concern is that disability teams and so-called professional practitioners often exclude people with similar challenges to me simply by being in a position of power. They don’t want to listen and make changes for the better. Hence why so many people end up accessing mental health services.** ”

Foreword

I have a six-year-old daughter who is imaginative, creative and can build the most amazing 3D constructions for her superhero dolls to have adventures in, telling incredible stories with complex plots. Given the right support, she is the type of kid who could be the scientist or engineer of the future, not afraid to question commonly accepted theories and bring a new step-change breakthrough to the world. However, she struggles to read or write. She also has great anxiety over new people, situations, certain smells, unpredictable events or loud noises and a trip out may end up in a melt-down if not managed.

She is what I would describe as a 'deep thinker'. What others don't see is her quietly contemplating why gravity doesn't pull the sun out of the sky or the way she watches with fascination as she learns about the latest satellite being launched into space, asking the scientists involved in the space workshop what an 'exoplanet' is. They also don't see when she cries to me at night, 'they think I'm a baby because I can't read or write Mum' or the love she expresses as I sing her to sleep each night in her rigid bedtime routine. Although she struggles with reading and writing, she is very astute and hyper-aware of all going on around her.

Occupational therapy and educational psychology assessments highlight dyspraxia/ development coordination disorder, sensory processing disorder, speech issues, potential auditory processing disorder, likely dyslexia and recommend that she is assessed for autistic spectrum disorder. We're still on the waiting list for a community paediatrician. The tests also confirm her strengths, with her achieving well beyond her peer group on things like logic, abstract concepts and block design. I took on applying for an Educational Health Care Plan Needs Assessment and one box in particular completely stumped me, 'primary condition' (with space for one word). The truth is there isn't one thing - it is a constellation of challenges that have a complex interplay between them. I sat pondering, which is the chicken or the egg and what came first, the fine and gross motor control issues or visual eye tracking that create a barrier to her reading and writing or the sensory issues that mean this along with all the other sensory overload at school is just the final straw? Or might it be the complex seizures she had as a toddler, or perhaps the recently diagnosed coeliac disease, combined with our family history, is actually at the root of it all?

It is only through my daughter's experience that I now realise why I had to pick up rubbish every lunch-time as punishment for being late to school, along with all the falls and knocking things over: I too probably have dyspraxia. I still struggle to get places on time and school drop-off truly challenges me. Thankfully my employer has a flexible working hours policy. When school ask me to help my daughter by giving her fine motor control tasks one-to-one, I feel embarrassed to admit I struggle with them myself and I am simply not able to sew 'long loops' onto her school clothing. My one saving grace is when it all gets too much, I can simply switch off my hearing aids and put the world on mute (I also have severe hearing loss). Like many adults though, I will probably carry on as one of the many faceless undiagnosed.

This report shares not just my experience, but the experience of over 500 other people with neurodevelopmental conditions and their parents and carers, many with much more challenging experiences and frustrations than mine. It includes recommendations for improving integrated research and support for people who can bring huge value to our society if they are better supported.

Join us in our call to action.

DIANE WASS

JPA Health Communications

Update note: At the time of printing, Diane's daughter is now 7 years old and has seen a community paediatrician who confirmed autism, ADHD, sensory processing disorder, dyspraxia and dyslexia, in addition to the previous history of complex seizures and coeliac disease. The ECHP process is ongoing.

Introduction

Many of us experience and interact with the world in different ways from others thanks to the make-up and behaviour of our brains.

Neurodevelopmental conditions (NDCs) affect up to 10% of the population and include autism, attention-deficit hyperactivity disorder, sensory processing disorder, epilepsies and / or seizures, developmental coordination disorder / dyspraxia, dyslexia, dyscalculia and many others, all linked by their presence generally from the earliest stages of life and their connection to the developing brain. The large majority persist into adulthood and are lifelong.

Historically, medical professionals have sought to distinguish between different neurodevelopmental conditions largely based on their outward presentation. But there is growing recognition that neurodevelopmental conditions often share symptoms and most people affected have more than one of these conditions and often many.¹

Yet, too often, services, charities and wider society are unaware of - and unprepared for - this complexity. People with NDCs are viewed through a lens of a single diagnosis, generally the first one they received in life, without regard to the complex variety of challenges they face.

Those challenges are often the same regardless of the neurological differences you might have. Issues with education, health, employment, criminal justice and social inclusion, to name just a few, are common. Combining forces to span the traditional diagnostic boundaries and find common solutions could have enormous impact. That's why a group of UK charities supporting people with NDCs or specialising in mental health came together to survey their members collectively on their experiences and better understand their needs.

“ Listen to people of the neurotype they're representing and take their opinions into account. ”

This report aims to stimulate further debate and discussion around the needs, desires and hopes of people diagnosed with neurodevelopmental conditions. Findings, both quantitative and qualitative, from the survey have been included to shed light on the shared experiences of a wide range of respondents.

We do not claim to have the answers and it's clear that far more widespread and rigorous research and consultation is needed but this report is the beginning of a much-needed conversation. We have included some preliminary recommendations where we believe action could accelerate more joined-up approaches and hence better outcomes for the people we serve.



JON SPIERS
CEO of Autistica and chair of the coalition



Survey Methodology

A group of 25 charities who support people with a range of neurodevelopmental-related challenges and conditions including mental health problems sought to understand how these affect those living with them. We wanted to learn about the realities of living with one or more neurodevelopmental condition (diagnosed or not) and how those affected perceive the help and support they receive from healthcare, welfare, social care, education, employers and society as a whole.

The survey questions included both multiple choice and free text answers and were developed by Autistica, a specialist autism research charity, with input from across the charities including review by people with

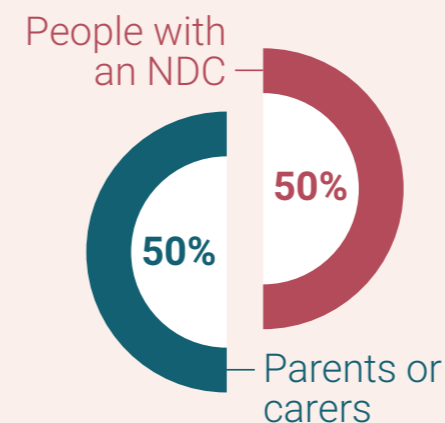
NDCs. The survey was distributed via Survey Monkey to 25 charities for publicising and completion by their beneficiaries in 2018. The survey could either be completed by people with NDCs or their parent/carer.

Questions explored areas such as the number of conditions people had been diagnosed with and believed they actually had, everyday challenges people face, diagnosis and support. Results were analysed by JPA Health Communications, an independent agency. Survey participant characteristics are shown on the right.

The key findings from the survey and recommendations are outlined in the following pages.

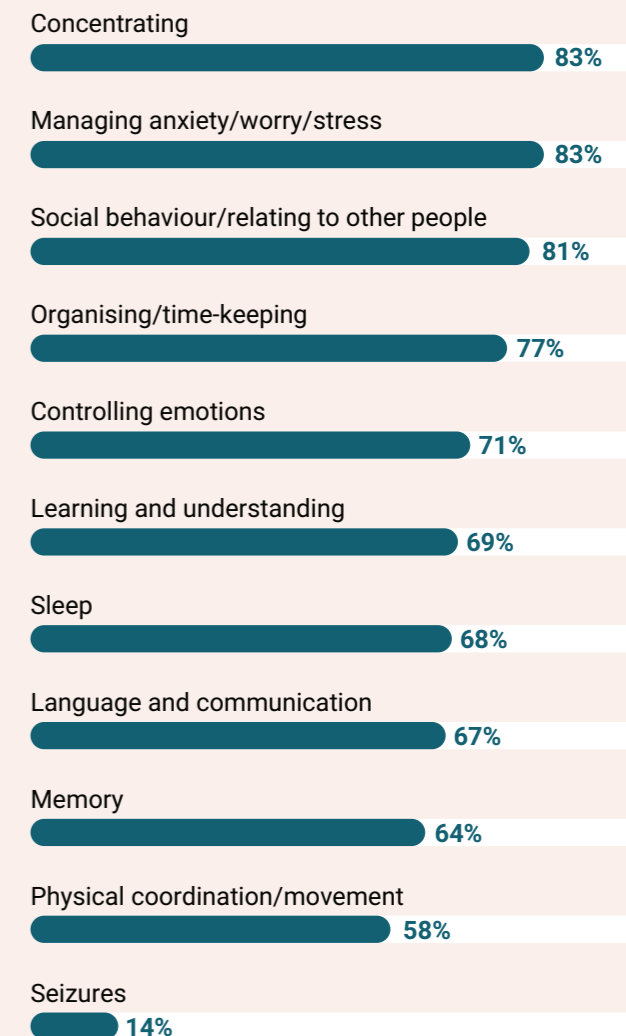
Survey Participant Characteristics

529 people completed the questionnaire:



Challenges

People were affected by problems with:



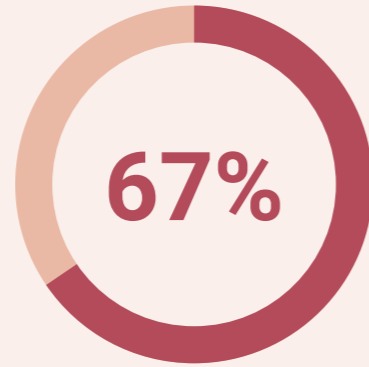
Explanatory note: As not all participants completed all questions, we are reporting percentages along with the baseline sample from which each percentage was derived.

Diagnosis

The majority of survey participants, nearly 9 in 10, had been formally diagnosed with at least one NDC. The survey was completed by themselves or with the aid of a parent/carer. It is important to note the survey was publicised through charities, where people with a diagnosis are more likely to have seen it.

The top 10 conditions listed by people who participated in the survey and had a diagnosis are shown to the right, with autism and developmental coordination disorder/dyspraxia being the most common. Other conditions listed that were not in the top ten included bipolar disorder, Fragile X syndrome, schizophrenia and speech sound disorder. A fifth of participants also said they had 'other conditions'.

Overall, 67% (n=520) of those surveyed (diagnosed or undiagnosed) had either been diagnosed with *more than one* NDC or believed they had *more than one*. When considering only those respondents who had been officially diagnosed, equivalent numbers of people had been diagnosed with a single NDC or *more than one* condition (192 vs.195 people).

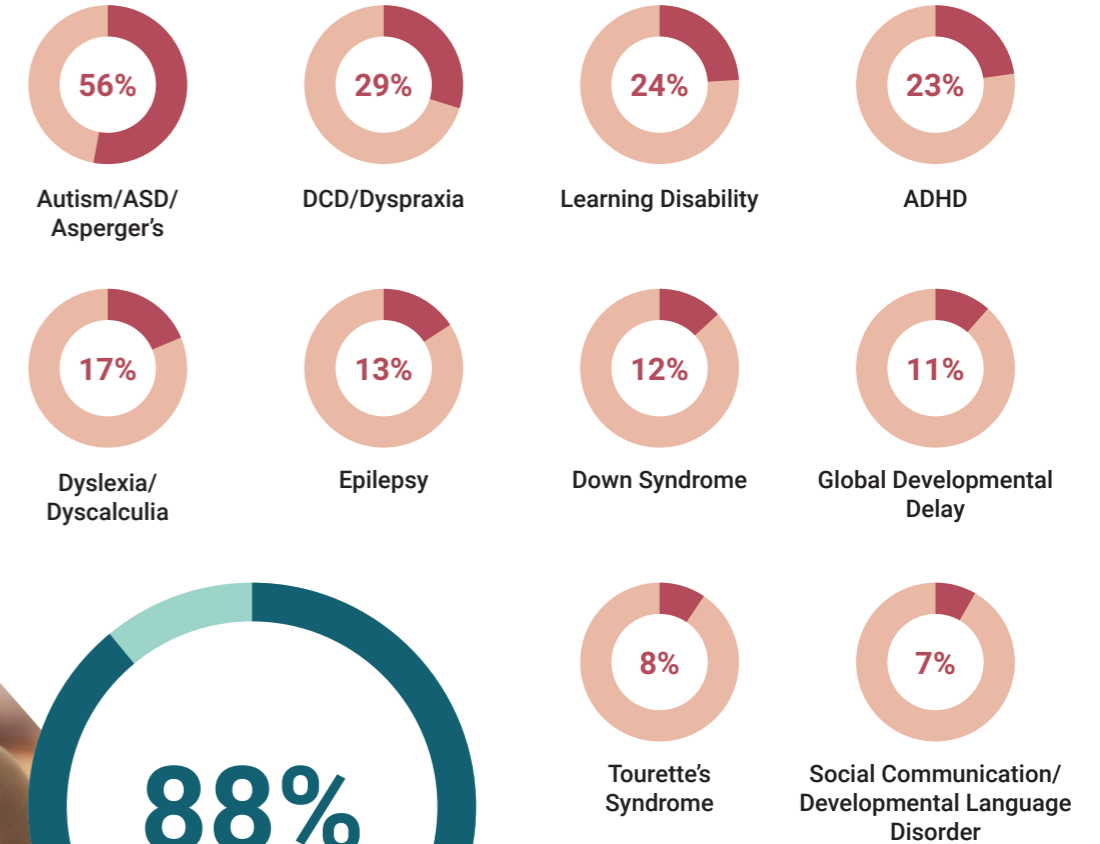


have or believe themselves to have more than one NDC

The majority of people who were already diagnosed said it was not easy to get a first diagnosis (58%). Difficulties included long waiting times to see a specialist, being told children were too young to be considered, and constant referrals to different healthcare or educational providers. Of those responders who had not yet been diagnosed, 58% of them had tried to get a diagnosis but experienced many of the same issues, as well as experiencing dismissive attitudes, not knowing where to go for help, and feeling lost in the system. A number of people talked about the need for better sign-posting for diagnosis.

Conditions most commonly diagnosed

among 529 survey participants:



formally diagnosed with at least one NDC

“ We have to manage his mental health, anger, upset and safety alone. We are utterly exhausted and frustrated at the lack of help available. ”

Support

On diagnosis, nearly half (46%; n=443) of individuals were not offered information or support to help them understand how the condition could affect their life.

At the point of diagnosis, 77% (n=447) of individuals were not made aware of other possible diagnoses which might affect them. This is despite the wide and growing body of evidence that many NDCs increase the probability of other conditions. For example, the increased prevalence of epilepsy in autistic people and the increased prevalence of autism among people with



OVER HALF OF RESPONDENTS
don't feel accepted in society or know where to go for help.

“ I have lost my job twice after I disclosed my autism. Employers don't want to recruit autistic people. I think they hate us. ”

epilepsy, compared with the general population, are now well established.² Conditions such as attention deficit hyperactivity disorder, anxiety and sleep disorders are also common in both epilepsy and autism.³ Similarly, the overlap between dyslexia and dyspraxia is now well-recognised, with one study for example showing 53% of people with dyslexia also having dyspraxia.⁴ When and how a person would like to be informed is an area where further research is needed to support informed choice. Health services should consider new pathways where a diagnosis of any NDC triggers a pro-active screen for further undiagnosed NDCs and other conditions.

Once diagnosed, there is an evident lack of support for most people with NDCs across health, education and public services. Most respondents reported that their physical and mental healthcare treatments don't take account of their NDCs (62% n=524), despite a clear majority agreeing with the scientific evidence that there is a connection between their NDC and other health conditions (69% n=527). 43% of respondents felt they could not access health services (n=527) and 40% (n=528) felt their additional support needs were not met to help them access health services. 44% felt they had been treated worse for a physical or mental health condition because they had an NDC (n=526).

Almost a third of respondents in education said the education system is not supporting them well (27%, n=312), but 41% (n=313) thought individual teachers/lecturers understood all of the different challenges they faced, highlighting the importance of training teachers to support children and adults with NDCs.

Of people in contact with social care and the welfare system (38% and 25% respectively, n=526), nearly half said their needs are generally not well supported by the social or welfare system (46%, n=197 and 46%, n=131) with this proportion rising further when it came to being understood (58%, n=197, 63%, n=133).

Nearly all, 94% (n=526), of those diagnosed said they need professional support. Over half of respondents do not feel accepted in society (53%, n=518) and don't know where to go for help (54%, n=498). This was particularly stark for adults in the qualitative feedback where there were numerous comments about services and support being geared towards children, but not recognising those children grow up to become adults.

“ Large class sizes and teachers under significant pressure to meet targets - this is not an environment conducive with meeting the needs of neurodiverse children. ”

Research

Research is the key to improving public services, changing attitudes and understanding better the common issues and the specific challenges faced by people with NDCs.

Although NDCs can have positive traits, without appropriate support and positive societal attitudes, they can be disabling, cause significant mental health issues, impact quality of life and increase the risk of premature mortality.³ The economic impact of NDCs on individuals and society as a whole can be huge, including care costs, lost economic productivity, state benefits, education support and the costs to criminal justice.

But despite NDCs affecting up to 10% of the population and often leading to lifelong challenges as well as advantages, research into neurodevelopmental conditions receives many times less funding than areas such as dementia, cancer or heart disease. State funders like the Research Councils and National Institute for Health Research should consider increasing funding into NDCs, with a particular focus on studies which include multiple NDCs.

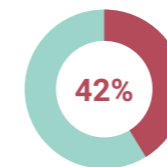
Until now, most of the relatively small number of 'trans-diagnostic' studies have focused on genes, showing that there is a common genetic basis for many NDCs. While

this is valuable research, there must now be a greater focus on research to understand the lived experience, identify shared needs, model shared cognitive and behavioural profiles and develop new ways to support people across the lifespan. Charities are particularly well placed to lead this research, given their close connection to the people they serve.

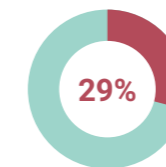
Our survey shows how many issues cut across traditional diagnostic boundaries, with the majority of respondents struggling with a range of areas including concentration, anxiety, sleep and social interactions. Studies focusing on approaches to these issues which work regardless of which NDCs a person may have could have major impact and would help very limited research spend to go further.

It is vital that people with NDCs and their families are engaged as partners in research, making clear their priorities, co-designing studies and supported to carry out research themselves.

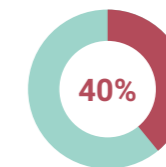
One recognised factor known to lead to neuro-developmental issues is experiencing traumatic birth conditions⁵ like pre-term birth and perinatal asphyxia. NHS figures show around one baby in 13 is born prematurely in the UK each year⁶, a key risk factor in developing NDCs that may require additional monitoring.⁷



42% of survey participants reported having a difficult birth (n=529)



with 29% of those needing neonatal care (n=222)



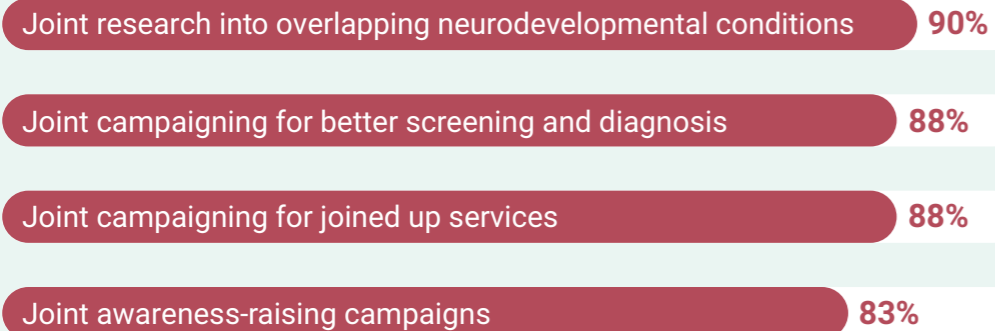
and 40% experiencing trauma such as loss of oxygen to the brain (n=224).

This data indicates the importance of follow-up support for people with pre-term and/or difficult births and further research.

So What Can We Do?

This report offers only a brief snapshot of the experiences of people with neurodevelopmental conditions and their families, but it highlights that they often have a variety of overlapping diagnoses and experience many common challenges regardless of diagnosis. The growing body of evidence around multi-morbidity and shared causes of NDCs indicates joint research, campaigning and awareness-raising is critical across these conditions.

In the survey, a strong majority either agreed or strongly agreed that charities should be joining forces (% shown below, n=507-514). Our community want to see us working together to create:



People felt well-supported by charities and also felt charities understood all the challenges related to their NDC (75% and 72% strongly agree/agree respectively; n=199, n=200). This collaboration between charities to understand the experiences of people living with neurodevelopmental conditions through our survey is a first step. However, there is a need for this joined-up approach to go beyond the charity sector and more funding is needed to support research and action.

Clinical, education and support service models need to adapt to meet this need. It is clear from the survey that the needs of people with NDCs and families are not adequately being met today. We invite you to join our call to action and continue this conversation to help drive a new approach to championing the needs of people living with neurodevelopmental conditions.

Call to Action

People who think and see the world differently have the potential to bring huge value and diversity of thinking to society, but also often face a complex and overlapping set of challenges.

To help people with NDCs and families achieve the best outcomes, it is critical that we – charities, research funders, public services and society – start to work together more effectively and seek opportunities to accelerate our impact.

Greater investment, integration and involvement of people with NDCs are needed in services and research, including in timely detection and diagnosis, accessing NDC-appropriate public services and providing the right supports across the lifespan.

Together, we can tackle stigma, improve outcomes, boost awareness, help limited funds go further and ultimately create a future where people with neurodevelopmental conditions and their families enjoy the same opportunities and experiences as the rest of society.



References

1. Gillberg, C., Fernell, E. and Minnis, H. (2013). Early symptomatic syndromes Eliciting Neurodevelopmental Clinical Examinations. *The Scientific World Journal*, 2013, pp. 1-2.
2. Besag, F. (2017). Epilepsy in patients with autism: links, risks and treatment challenges. *Neuropsychiatric Disease and Treatment*, Volume 14, pp. 1-10.
3. Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bolte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(03), pp.232-238.
4. Stothard, S., Snowling, M., Bishop, D., Chipchase, B., & Kaplan, C. (1998). Language impaired preschoolers: A follow-up into adolescence. *Journal of Speech, Language and Hearing Research*, 41(2), 407-418.
5. Rauch, S., Lamphear, B. (2012) Prevention of disability in children: elevating the role of the environment. *The Futures of Children*; 22: 193–217
6. Office of National Statistics. (2011) Live births in England and Wales by characteristics of the mother.
7. Foulder-Hughes, L. and Cooke, R. (2007). Motor, cognitive, and behavioural disorders in children born very preterm. *Developmental Medicine & Child Neurology*, 45(2), pp.97-103