My First
1000 Days

‘Nothing About Us Without Us’: Our Blueprint for Inclusive Family Support

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> ***‘The people running things need to be educated and willing to learn.’***

We are a group of disabled parents and parents of disabled children who volunteered to help a team at the University of Leeds who are developing a new kind of support for families with young babies living in Leeds. It’s called the *My First 1000 Days* programme, and it's different from anything else we have come across.

It's not your typical ‘experts talking at parents’ initiative. Instead, the idea is to bring together mums, dads, grandparents, foster parents – whoever is caring for the baby – to meet eight times over six months, starting when babies are about six weeks old. They will meet at community centres near where they live, and talk about what they're going through, figuring things out together in a hopefully friendly, safe space. The groups will be somewhere to share worries and joys, to learn from each other and learn together.

The *My First 1000 Days* groups will discuss things like healthy foods and how to feed their babies, ways to stay active when you're exhausted, and how little ones develop and learn. There will be opportunity to talk about practical matters that can worry families, like how to access financial support if they need it, safe sleeping (because every parent is terrified of doing that wrong), what to do when you are feeling stressed and a baby just won't stop crying and how to make the home safe without having to buy a lot of expensive equipment.

What caught our attention was when the *My First 1000 Days* team said they knew disabled families need more than just token inclusion. They told us they wanted disability inclusion to be a ‘golden thread’ running through the programme, and not just an afterthought. That's when we thought*, ‘Okay, these people might actually be listening – now what do they need to know to make this happen?!’*

As disabled parents and parents of disabled children, we brought our lived experiences to two intensive workshops. We wanted the team to *know* about the barriers we face, to *understand* the impact of these barriers on our families, to *feel* our frustrations and joys, and to *do* something meaningful to change how early years support works for families like ours. Here's what we shared.

‘We want you to know about the barriers we face’

‘I avoided 'normal' play groups in the early days.’

Some of us have struggled to find supportive family groups, despite actively seeking information from midwives, health visitors and GPs. *Many* of us have felt excluded from services meant to support all families and actively avoided 'mainstream' family-focused groups of one type or another. We didn't need to explain *why* to each other—we all understood that feeling of being the 'different' family, the ones whose faces don't fit, whose children don't meet ‘expectations’, whose needs aren't accommodated. We've all endured the awkward stares, felt others' discomfort, fielded intrusive questions, and internalised hurtful observations. We've smiled politely through expressions of pity (*‘I don't know how you do it!’*) and patronising approaches that cast us as inspirational superheroes just for parenting our children.

Attending any parent-child group can be a challenge – not just emotionally, but physically. *‘Blue badge spaces are important,’* we pointed out. *‘It's no good having sessions at places with only one or two accessible spaces if lots of disabled families are coming.’* Some of us have found that there are times when we can't even enter the building—when entrances have narrow doorways and small lifts that can't accommodate our specialised equipment (e.g. buggies). Environments that are too loud, crowded, or bright can be completely overwhelming for some of us and our children—triggering sensory overload that makes participation impossible.

The way support programmes are structured often ignores the realities of our lives. *‘Sessions need to be flexible,’* we emphasised. *‘Disabled families have more appointments that clash, and we're more prone to illness. We miss sessions more often.’* When we miss a session, we're often left behind, with no way to catch up on what we've missed.

While mainstream services exclude us, we're simultaneously exhausted by navigating the complex, fragmented specialist support systems that are supposed to help us, and being forced to explain, over and over again, the needs of our child and family. We wanted the *My First 1000 Days* team to understand that the constant need for self-advocacy is draining:

*‘We **waste so much time and energy** finding our own support.’*

*‘Already stressed parents are expected to source information themselves **without guidance**.’*

*‘You repeat yourself **all the time**.’*

We're constantly explaining ourselves to professionals who should know better. As one of us put it: *‘Our 'specialist' health visitor couldn't even remember my child's name or disability—I was educating them!’* We're tired of *‘constantly fighting to be heard’* and dealing with professionals who are *‘dismissive and patronising.’* It's draining to be treated like you're overreacting when you know your child better than anyone.

Any new programme needs to recognise this dual challenge—we're excluded from mainstream services but also let down by specialist provision. So, when facilitators of the *My First 1000 Days* groups meet disabled families, they need to understand that we are not starting from a place of trust. We have often had to fight for basic services that others take for granted. We've developed protective barriers around ourselves and our children. Understanding this context is about recognising the very real experiences that shape how we approach new services and what it will take to earn our trust.

‘We want you to understand how it feels to be treated like problems to be solved’

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*‘Those **awful** child development questionnaires!!! Hated those, they just made you feel like your child wasn't 'normal'... **what even is normal**?!’*

What frustrates us most is how health and social care professionals often make us feel judged, dismissed, or patronised. They see our children and families as problems to fix rather than people to support. Disabled parents feel constantly watched and evaluated, with our parenting abilities questioned in ways that other parents don't experience – but this can apply to parents of disabled children as well.

The constant measuring of disabled children against ‘normal’ development is exhausting. A member of our group shared how a healthcare professional diminished her daughter's hard-won progress:

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*‘We were so proud of her. For our daughter, any progress is a **major** thing. But the doctor said, 'Well, she's not developing like a **normal** child, is she?'‘*

The dismissal in that question cut deep.

We've had enough of development forms *‘where every tick is in the 'no' box’* and professionals focusing on *‘age-related milestones’* that may not be appropriate for our children. These make us sad.

‘We want you to recognise our specialised needs’

> *‘If I saw feeding on the programme list, I just wouldn't have come. My child was tube fed and on specialist food. I would have felt I* ***wouldn't belong****.’*

We understand that nutrition and feeding are important topics for any early years programme. But for many of us, those discussions can feel incredibly alienating when they only cover what's considered ‘typical’ feeding.

Our experiences with NG (nasogastric) tubes show how complex our feelings can be. One of us felt disconnected by this experience, because *‘the mother-child bonding is taken away when you're not breastfeeding.’* But another found a different way to connect: *‘I wanted to learn how to manage the NG tube myself because it made me feel like I was the one feeding my baby.’*

For the *My First 1000 Days* team to properly include families like ours, they need to acknowledge all the different ways we feed our children. Not just breast or bottle, not just purées or baby-led weaning, but tubes, syringes and specialist formulas too. When facilitators recognise these as valid approaches rather than medical ‘problems’, it makes the difference between feeling like outsiders or feeling genuinely included.

‘We want you to feel the joy our children bring to us’

> *‘During her first bath in hospital she kicked and moved her legs for the first time. Five years later she says she wants a 'relaxing bath'!’*

Despite the barriers we face, our lives are not tragic and we want to share the moments of connection and joy that make it all worthwhile—moments that professionals often fail to see when they are focused on what our children can't do.

When we were asked to describe moments of joy with our children we had no difficulty finding lots of examples: *‘Her hands flapping with excitement,’ ‘A huge smile at just hearing 'hi ya!',’ ‘The way he jumps up and down to music,’* and *‘That little giggle during peekaboo.’* These are the moments that matter to us—not whether our children are meeting someone else's idea of ‘normal’ development. These are the milestones that don't appear on any chart but mean everything to us.

We celebrate our children's unique ways of being in the world.

But we also acknowledge the complex emotions that come with parenting – whether that is as a disabled parent, parent of a disabled child (or both): *‘Guilt is probably the most common emotion in* *parenting,'* one of us shared. We experience feelings of being *'judged',* feeling *'inadequate,'* and know we sometimes become *'guarded and defensive.'* We need spaces where we can admit that *'it's okay to sometimes wish things were different'* without being criticised or seen to be a 'bad parent'.

'We want you to do what would make a difference'

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*'Trust your own judgement – **nobody knows your child better than you**!*
(But they will try to convince you otherwise)'

When we were asked what would work better, and ensure that support programmes that are meant to be disability-inclusive *truly are*, we had plenty of ideas. We need physical spaces that are truly accessible—not just meeting minimum requirements but genuinely welcoming for our diverse needs. This includes sensory-friendly environments – as one of us put it, we need: *'Quiet sensory spaces are essential so parents and children can retreat to a safe space when needed.'* And we want these spaces to be designed with purpose, not an afterthought or a converted storage cupboard!

We need flexible programmes that understand our complex lives, allowing us to attend in different ways and catch up when we miss sessions. We'd like programmes not to be *'too restrictive on family members'* – allowing *'personal assistants, siblings, grandparents'* to attend. We'd like sessions offered at various times and in hybrid formats so we can participate in ways that work for our families.

Most importantly, we need professionals who **respect our expertise**.

We were clear about what we expect from people running early years programs: *'Facilitators need to be educated and willing to learn about disability,'* we emphasised. *'They should actively seek knowledge about things they don't understand'*. We want them to use *'exploratory questions rather than telling us what to do.'*

For topics like feeding, we need inclusive approaches that *'cover all options*'. When the only talk is about about breastfeeding or bottle feeding, it immediately signals to many of us that this space isn't for families like ours. We need messaging about physical activity that's *'realistic and pressure-free'* – recognising that *'the school run counts as exercise*' and encourages us to get *'fresh air'* and '*do what brings you joy.'*

'This is what truly inclusive early years support could look like'

We don't want special treatment. We want services that are designed from the start to include everyone. We want disability inclusion to be a fundamental principle, not an accommodation or afterthought. We want to be seen as parents first, not as a collection of diagnoses and challenges.

We need practical support: information about equipment sharing networks, guidance on navigating benefits and funding, first aid training specific to our children's needs, and realistic approaches to sleep, feeding, and physical activity that recognise the diversity of our experiences. We need this support delivered in ways that don't require us to jump through endless hoops to access it.

We need emotional support too: recognition of the stress we're under, help with sleep deprivation, stress management techniques, and protected time for self-care that some of us consider *'essential, not optional.'* And we need connection with others who understand—spaces where we can share without judgment.

Most of all, we need society to shift its perspective. Stop seeing our families as deficient or tragic. Stop measuring our children against narrow standards of 'normal' development. Start recognising the knowledge we've gained through our lived experience. Start designing services that make space for all kinds of families, all kinds of bodies, and all kinds of children. We want support to be strengths-based.

Through the *My First 1000 Days* programme, we've had a chance to help create what early years support could look like if it actually centred our expertise rather than treating us as problems to be solved. The team seems to be committed to including families like ours from the ground up, building something that truly works for everyone.

These workshops weren't just about helping the research team tick their inclusion box. They gave us the chance to meet other families going through similar challenges – and some different ones too, because no two families are the same. We've even started a WhatsApp group and still keep in touch. That connection alone has been invaluable.

We're keeping an eye on how this all unfolds. The team made some big promises about this 'golden thread' of disability inclusion, and we'll be holding them to it. Will they really make the changes we suggested? Will our voices actually shape what happens next? Or will it be the same old story of 'thanks for your input' and then business as usual?

Time will tell, but we're cautiously hopeful – and we're definitely not going anywhere. We'll be watching, advising, and yes, keeping the *My First 1000 Days* team on their toes every step of the way. Because this isn't just about creating another programme – it's about changing how society supports families like ours in those crucial first 1000 days.

As one of us put it, perfectly: ***'We should not change to meet society's needs – society needs to change to meet ours.'*** And we mean it.

We are the disabled parents and parents of disabled children who participated in the My First 1000 Days workshops at the University of Leeds, sharing our experiences to help create more inclusive early years support for all families.

RESEARCHER NOTE

‘When we began developing the My First 1000 Days programme, I knew that meaningful inclusion wouldn't happen by simply retrofitting disability considerations onto an already-designed intervention. That's why we conducted these intensive workshops (two 4-hour sessions) at a specific point in our development process—when families' insights could genuinely inform every aspect of the programme.’

‘As the workshop facilitator, I wanted to create a space where disabled parents and parents of disabled children could speak freely about their experiences and have their expertise recognised. Their input isn't just influencing superficial elements—it's shaping how we advertise the programme, our messaging about its objectives, our session plans, facilitator training materials, and implementation guides.’

*‘Will we get everything ‘right’, fully, first time round? **I doubt it**, because what we are trying to do is not easy. But we will do our very best, and we will listen to disabled families who join the My First 1000 Days programme and make further adjustments as we go. In other words, we will be responsive and learn from feedback.’*

‘What struck me most during the workshops was how quickly the group formed connections and how generously they shared their knowledge. Their willingness to engage with difficult topics—from exclusionary professional practices to moments of joy in parenting—provided insights that no literature review could capture.’

‘The workshops embodied what I call ‘radical listening’—moving beyond token consultation to create spaces where families can articulate their expertise and challenge normative assumptions. This approach recognises that meaningful inclusion requires a fundamental shift in power, positioning disabled families not as passive recipients of services but as essential knowledge-producers who should be central to their design.’

‘The My First 1000 Days programme will be better because of these families' contributions, and we are incredibly grateful for the time they gave and their wisdom. We remain committed to ensuring that disability-inclusion truly is a ‘golden thread’ running through everything we do.’

Professor Angharad Beckett, Co-Investigator, My First 1000 Days Project