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Challenging attitudes and language around Down syndrome: The lived experience of a proud mother

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By Nicola Enoch

Improvements in the UK's maternity services all happen thanks to the efforts of a diverse range of people and organisations. In this article, Nicola Enoch tells AIMS about how she has drawn on her personal experience – where she discovered a need for improved information and support around Down syndrome – to move into the world of peer support, national policy work and campaigning. Nicola's inspiring account of her steadfast commitment and achievement serves as a reminder of just what 'ordinary people' can do and demonstrates the key role of those with a service user perspective in driving improvement and change.

Seventeen years ago, when pregnant with my second child, I was firmly of the view that I did not want a baby with Down syndrome – or as I'd have thought then, a Down's baby – a baby defined by and limited by its disability. When I reflect now, I can see how desperately ignorant I was, misinformed and misled. Society and medical practitioners led me to believe that one didn't want one of 'them', an unknown entity that we screened in order to avoid.

I'd found myself on the conveyor belt to termination – completely against all my hopes and dreams and absolutely terrified. Booked in for an amnio, my husband and I had never particularly discussed termination, but it was the unspoken default – what everyone did, what the medics steered you towards, aware it would all be dealt with quickly, discreetly and then we could try again for a baby who was healthy, no problems, and with no chromosomal abnormality…

Having suffered 4 miscarriages before our beautiful daughter Emily had been born, I had endured my share of pain and grief, and so, with fear of a miscarriage and in the hope that nature surely wouldn't be so cruel again, I decided to cancel the amnio. It turns out to be the best decision I've ever made. Although I didn't think that, a few months later, when my gorgeous baby boy Tom was a day old and a paediatrician awkwardly and clumsily expressed 'concern' that Tom may have Down syndrome and asked me if I thought 'he looked normal'.

My world fell apart. I regretted cancelling the amnio and feared our lives were now ruined. Emily no longer had a beautiful baby brother; he'd been replaced by a burdensome sibling. I couldn't envisage what Tom's life would be like as I had no knowledge or experience of Down syndrome – I imagined rejection, segregation, isolation…that Tom would have to go to a special school, that as a family our lives would be dominated by Down syndrome, a future full of medical appointments, awkward stares and embarrassment, people pitying us, specialist equipment. I feared we'd entered a world we'd been led to believe we didn't want to be part of, and so found ourselves considering having Tom adopted. It sounds extreme when I try to condense my feelings into a paragraph, but the fact is that complete fear and utter despair overwhelmed me.

I'd clearly rejected Tom and feared I'd never love him as I did Emily; but in time I fell back in love with him, and now I couldn't be prouder or love either Emily or Tom any more than I do. As Tom started to show me that he was nothing to be feared, not a risk or a burden but rather a wonderful little boy who made my heart swell with love and pride, I started to question why I'd felt such despair and fear. I realised how influenced I'd been by medical language and attitudes, by my lack of knowledge or contact with anyone with Down syndrome, by society's derisory and prejudicial views towards those with any sort of a learning difference and the blatant discrimination that is levelled towards those who are not perceived to be normal, to be acceptable.

When Tom was 18 months old I started a local support group, The Ups of Downs[1], in Warwickshire. Over the years I realised I was never meeting any parents who'd discovered whilst pregnant that their baby had Down syndrome, just parents who had all too often struggled in the early days as I had. It has been a long journey of discovery – realising how negative and discriminatory attitudes towards those with Down syndrome prevail in maternity services. For expectant and new parents, very little accurate information is provided, and inappropriate or non-existent support is given to parents when they are at their most vulnerable and in need.

And so, in 2017, I created Positive about Down syndrome[2] (PADS), initially as a website full of stories and photos. The stories are written by young people with Down syndrome and their friends and families, and the aim is to share the reality of our everyday lives. I hope that in this way we support other families with what they yearn to know: “What will our lives look like?”

PADS has a strong presence on social media and we have gone on to create online support groups for expectant mums[3] – whether they have a high chance or a confirmed result of their little one having Down syndrome – and a group for new parents[4]. These pages offer amazing support and I am immensely proud of them, as I can see, on an almost daily basis, how beneficial they are to our expectant and new parents. I don’t want any parent to feel alone, to be scared of the future, when the reality is that there is nothing to be scared about, that a child with Down syndrome fundamentally has the same needs as any other baby. Whilst approximately 15 to 20% of babies with Down syndrome require heart surgery, the outcomes are generally very good. I am astounded at how strong and resilient most of our babies are! Just recently we had one little girl, Matilda, undergo open heart surgery, closing an ASD (atrial septal defect) and large VSD (ventricular septal defect) on a Wednesday morning. She was home Friday evening.

I also started to campaign and lobby for change as I became more aware of the lack of information and support for our expectant and new parents, along with discrimination towards Down syndrome. In 2019 at the Houses of Parliament, we published a research report – Sharing the news[5] – which corroborated the anecdotal stories. I was hearing of women being pressured to terminate, and decisions not to screen or to continue a pregnancy regularly being questioned and undermined, along with a shocking amount of ignorance, misinformation and lack of support.

Sharing the news

This is a survey of 1,410 women who have given birth to a baby with Down syndrome since 2000, conducted by PADS in 2018, in conjunction with Don’t Screen Us Out (DSUO)[6] and the Down’s Syndrome Research Foundation UK (DSRF)[7]. Responses reveal that there is a general assumption by medical professionals that an expectant woman will terminate when discovering her baby has Down syndrome. The report also finds that:

On receiving news that the baby had Down syndrome:

- 69% of women were offered a termination.
- After advising that they were continuing with the pregnancy, 46% of women were asked again if they wished to terminate.

On receiving news that the baby had a high chance of having Down syndrome (greater than 1:150):

- 91% of women were offered further tests.
- Of those who declined further tests, 44% felt under pressure to test further.
- After advising they were continuing with the pregnancy, 50% of women were offered a termination again.

Antenatal screening:

- 41% of women were of the understanding that screening for Down syndrome was a routine element of their antenatal care.
- 41% of women advised professionals that they did not want to screen for Down syndrome.
- After advising that they didn’t want to screen for Down syndrome, screening was mentioned again to 49% of women.

There has never been an RCOG (Royal College of Obstetricians and Gynaecologists) pathway for those women continuing a pregnancy with a high chance or confirmed result of baby having Down syndrome, only an RCOG pathway for those choosing to terminate: this speaks volumes about attitudes and priorities. In 2019, PADS was approached by St George’s Hospital (Tooting, South London) to collaborate to produce such a pathway, together with the Down Syndrome Research Foundation and we were delighted to recently publish this.[8]

In June 2020 we published #NobodyToldMe the truth about Down syndrome[9] – a collection of experiences written by young people with Down syndrome and their friends and families, and we are delighted with the response. We have already distributed over 2,000 copies. We gift a copy to all our expectant and new parents and have some funds to provide copies to maternity units. PADS has appointed a Maternity Co-ordinator as we are keen to build relationships with local maternity units, provide literature to signpost parents to our website and online support groups, connect hospitals with their regional support groups and provide training. We are presently collaborating with Health Education England to produce an eLearning module which we hope will be available before the end of 2021.

Seventeen years ago, I was terrified and felt desperately alone. Today, I often wonder how I could ever have considered our lives would be better without Tom. He has taught us all so much, and without a doubt has enriched our lives. It saddens me that on a daily basis, women in the UK are making life or death decisions without the information and support they deserve, that new parents are left feeling devastated and scared and that expectant parents are anxious and alone. PADS is here to support those parents, as well as educate and inform medical professionals about the reality of living with Down syndrome in modern Britain. We hope that both parents and professionals are empowered by such knowledge.

Author bio: Nicola Enoch is a founding trustee of both The Ups of Downs and Positive about Downs Syndrome. For more than 15 years, Nicola has been passionate about improving the lives of those with Down Syndrome, and their families, and she has worked with a wide variety of stakeholders to achieve this goal.

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1 upsofdowns.co.uk
2 positiveaboutdownsyndrome.co.uk
3

www.facebook.com/groups/415274562687672

4 www.facebook.com/groups/2188980851370457

5 downsyndromeuk.co.uk/flipbook.html

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