

I SEE YOU

Parent carers

stories told through stitch and words

Lead artist/maker Lois Blackburn



‘Art is very powerful and connects us with our inner life without realising.’

Tracey

Lead artist, project coordinator, photography, book design, editor

Lois Blackburn

<https://loisblackburnartist.uk>

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Becky Hague Fairplay

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Introduction

Welcome to **I SEE You**, a project dedicated to amplifying the voices and experiences of parent carers of children with non-visible disabilities.

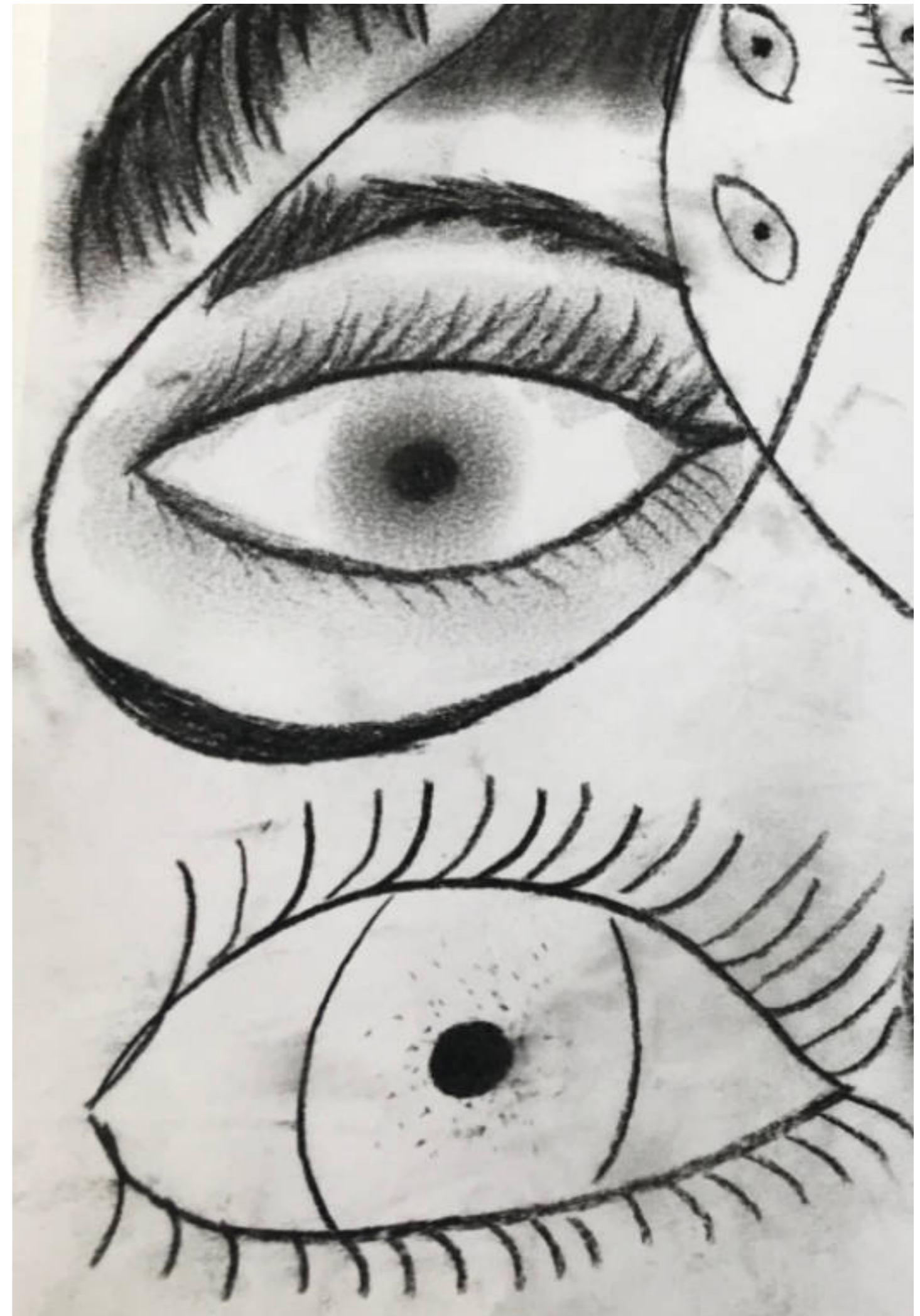
This collection of artwork is more than just a visual display—it is a testament to the unseen challenges, resilience, and love that define the lives of these families.

Parent carers navigate a world that often overlooks their struggles, misinterprets their needs, or fails to recognise their reality. Through art, this project brings visibility to their stories, offering a platform for expression, connection, and understanding.

Each piece in this catalogue reflects personal experiences, emotions, and perspectives, **making the invisible, visible.**

By engaging with this work, you are bearing witness to lives that are frequently misunderstood or ignored. We invite you to see, to listen, and to reflect. In doing so, we hope to foster greater awareness, empathy, and change.

Thank you for taking the time to explore **I SEE You**. Your presence here is an act of recognition.



What are non-visible disabilities?

Non-visible disabilities are physical, mental, or neurological conditions that aren't immediately apparent.

Around 70% of disabilities in the UK are non-visible, and more than one in five people will experience a disability in their lifetime.

Because these disabilities aren't obvious, individuals may face misunderstanding or judgement.

Examples of Non-Visible Disabilities:

Asthma – A long-term condition affecting breathing. While manageable, severe cases can be life-threatening.

Autism – A developmental disability affecting communication and interaction, with around 700,000 autistic people in the UK.

Coeliac Disease – An autoimmune reaction to gluten that damages the gut and affects nutrient absorption.

Type 1 Diabetes – A condition where the body cannot produce insulin, requiring lifelong management.

Epilepsy – A brain condition causing repeated seizures, with various types and severities.

Foetal Alcohol Spectrum Disorders (FASD) – A leading cause of learning disabilities, often misdiagnosed or misunderstood.

Inflammatory Bowel Disease (IBD) – Conditions like Crohn's Disease and Ulcerative Colitis cause gut inflammation and pain.

Tourette Syndrome – A neurological condition causing involuntary movements and sounds (tics), affecting both children and adults.

Understanding non-visible disabilities helps create a more supportive and inclusive society.



Challenges faced by parent carers

Parent carers of children with non-visible disabilities face constant challenges, often due to a lack of understanding and support.

They must fight for diagnoses, services, and school accommodations, all while battling stigma and judgement. Their child's needs are frequently misunderstood, leading to isolation and emotional exhaustion. Financial strain is common, as many reduce work hours or face high costs for therapies and care.

Relationships and family life can suffer, with little time for self-care. Navigating healthcare and transitioning to adulthood add further stress.

Despite their resilience, many parent carers feel overlooked and unsupported in a system that demands they constantly advocate for their child.

Why the eye?

The theme of this project directly addresses the hidden nature of disability. Participants embroidered images of eyes—each one a deeply personal reflection of their experiences as parent carers.

I wanted to create something bold and direct, something that would catch your eye and challenge the perception of what it means to be a ‘invisible carer.’

These embroidered eyes stare back at you—some vulnerable, many filled with tears, others wide awake at 4 a.m. But all are filled with love.

Inspirations Behind the Eye

I drew initial inspiration from the Surrealists, who often recontextualised and multiplied eyes to unsettle complacent attitudes about art and life.

By using the eye in this way, I invite the viewer to pause, to question, and to truly see the stories behind these works.

Another source of inspiration comes from the ancient symbol of the Evil Eye, which dates back over 5,000 years and appears in cultures around the world. Traditionally, eye talismans are used to ward off the ‘evil eye,’ confronting like with like.

Our I SEE You embroidered eyes serve a similar purpose—they confront and acknowledge, making the invisible visible.





The complex eye

Beyond its symbolism, the eye holds a deeper connection to one of the non-visible disabilities represented in this project. For some people on the autism spectrum, eye contact carries layers of complexity:

“For a long time, I didn’t know I was avoiding eye contact. I don’t like people looking at me, so if I don’t look at them, I don’t see them looking at me! It’s about being judged, about hiding who you are. As I get older, I care less, but I still have to make myself give eye contact. I hide it by looking behind them, or at the floor or window. The hardest part is listening and looking at someone at the same time.” **Parent Carer**

“When I’m talking, I look away, trying to verbalise my thoughts. I find it difficult being perceived by other people. I’ve never had a typical birthday party—only ever invited two or three friends.” **Parent carer**

By focusing on the eye, this project acknowledges the perspectives of children, parents, and the audience itself. It invites us all to see—to witness, to understand, and to reflect.





Connecting with parent carers

Creativity, Self-Care, and Shared Stories

How do you reach parent carers and encourage them to get creative, relax, focus on self-care, and share their stories?

Caring for someone can be incredibly rewarding, but it can also be exhausting, placing huge demands on both physical and emotional energy. One of the biggest barriers for parent carers is simply finding the time for themselves amidst their 24/7 responsibilities.

Making It Work for Busy Lives

This project was designed to fit around people's demanding schedules. I ran (insert number) free workshops in partnership with support groups and charities across the UK.

For those who couldn't attend in-person sessions—people with complex caring duties, those who are hard to reach—I offered postal packs with all the materials needed, backed up with optional Zoom classes.

In numbers

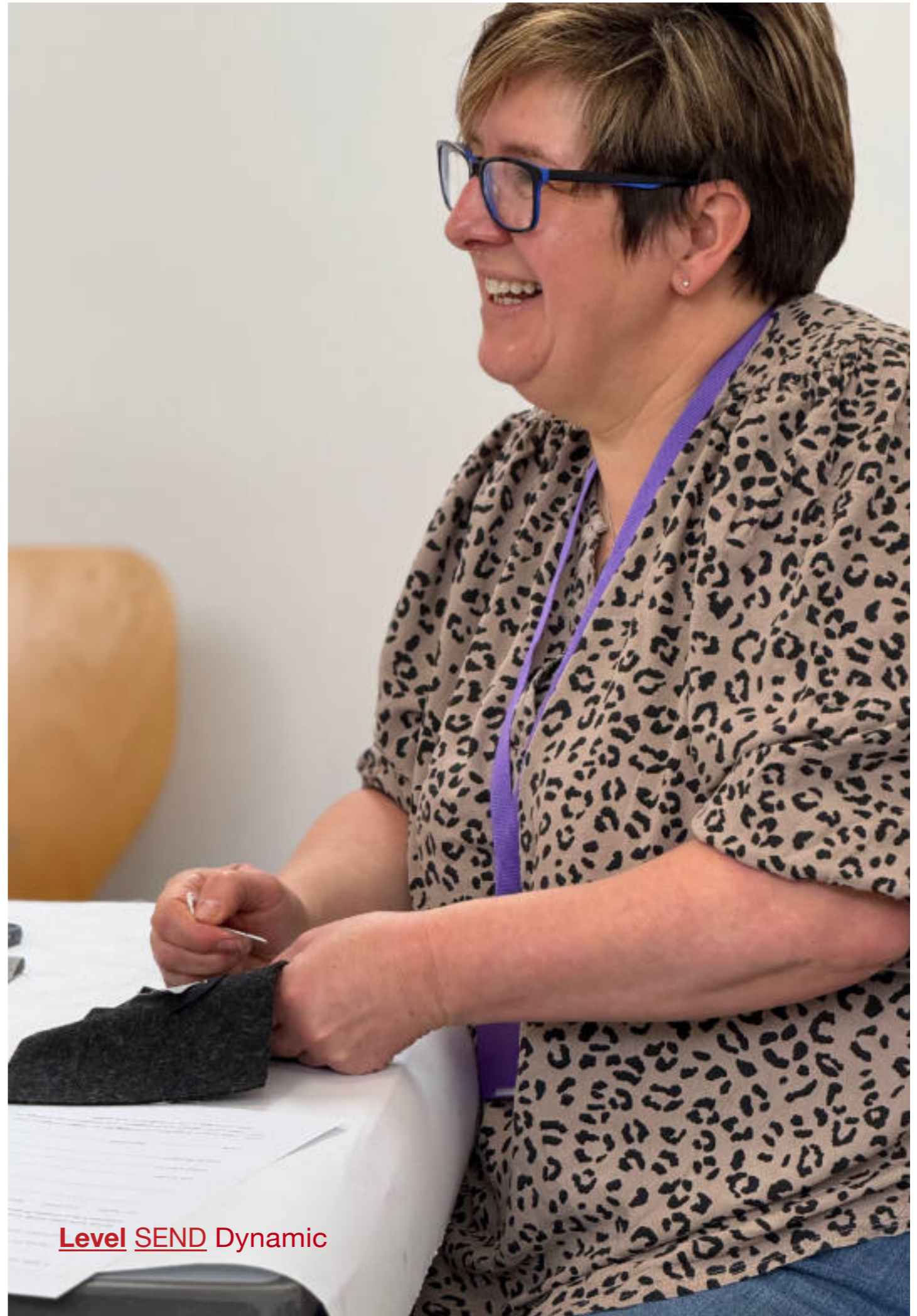
I ran **42** group workshops.

Delivered **80** postal packs.

Worked with a total of **224** people

Together we created: **122** embroidered eyes





Level SEND Dynamic

The making of a quilt

The embroidered eyes were created by a wide range of people—some confident artists, others who hadn't sewn since school.

Many felt uncertain about their skills, and almost all were pressed for time. Taking space for themselves was a challenge, but when given a creative task, they proved (unsurprisingly!) to be masters of time management.

Workshops were free to join in, with all materials provided.

Participants started by doodling eyes while I introduced the project. Some arrived feeling drained or caught up in a crisis, but the support group staff, volunteers, and fellow participants were always there to help. Given that support, most found joy, catharsis, and focus in making something with their hands.

For those who couldn't finish in the session, I provided a stamped addressed envelope so they could complete their work at home. That said, the majority completed their embroidery within the 2–3 hour sessions.

We laughed, we cried—but I always left sessions feeling inspired and uplifted.

'I really enjoyed the workshop, Lois has a really calming nature, and is great at gently encouraging you to join in, and nurturing your creativity. I was really surprised at how well my piece turned out, as it's not something I have done before.' Sarah





Talbot House
Manchester



Fairplay Dronfield

Bringing it all together

Once I received the embroidered eyes—either at the workshops or through the post—I photographed each one and added it to a database.

Then came the process of arranging them on my design wall, carefully considering how each piece worked alongside the others. I spent (insert number) days rearranging, making sure each placement felt right.

The final quilt was stitched together by me, carefully combining the work of parent carers from across the UK—and even contributions from the USA and Spain!

It's always a huge responsibility to honour the work created in these projects. People have poured their hearts into their embroidery... sometimes even pricked their fingers and bled onto the fabric! (Those pesky sewing needles!)

To give the quilt structure and strength, I created a fabric sandwich: embroidered eyes on top, batting in the middle, and backing fabric underneath. I quilted it all together, finishing with a neat edging.

A collective story

Now, this work takes on a new life. Each participant placed their trust in me, sharing a piece of their story through their embroidery. Now, together, these individual pieces form something much bigger—a shared story of love, resilience, and creativity.

Through this catalogue and the touring exhibition, I hope this work connects with you. Maybe you'll share it with someone feeling alone or overwhelmed. Maybe a friend, a relative, a teacher, or even an MP who needs to hear these stories.





STORIES

The power of being seen

Parent carers of children with non-visible disabilities navigate a world that often fails to acknowledge their struggles, their joys, and their profound love.

They walk an uncharted path—advocating, protecting, and nurturing—while their own identities, needs, and emotions frequently fade into the background.

The ‘I SEE You’ project became a sanctuary, a space where parent carers could reclaim themselves, be heard, and express their journeys through art.

Here, their voices come together in an intricate tapestry of pain, resilience, connection, and love.

The weight of invisibility

‘Because I feel invisible, the project's intention spoke deeply to me. It gave me time to think about representation and be part of something bigger than my family unit.’

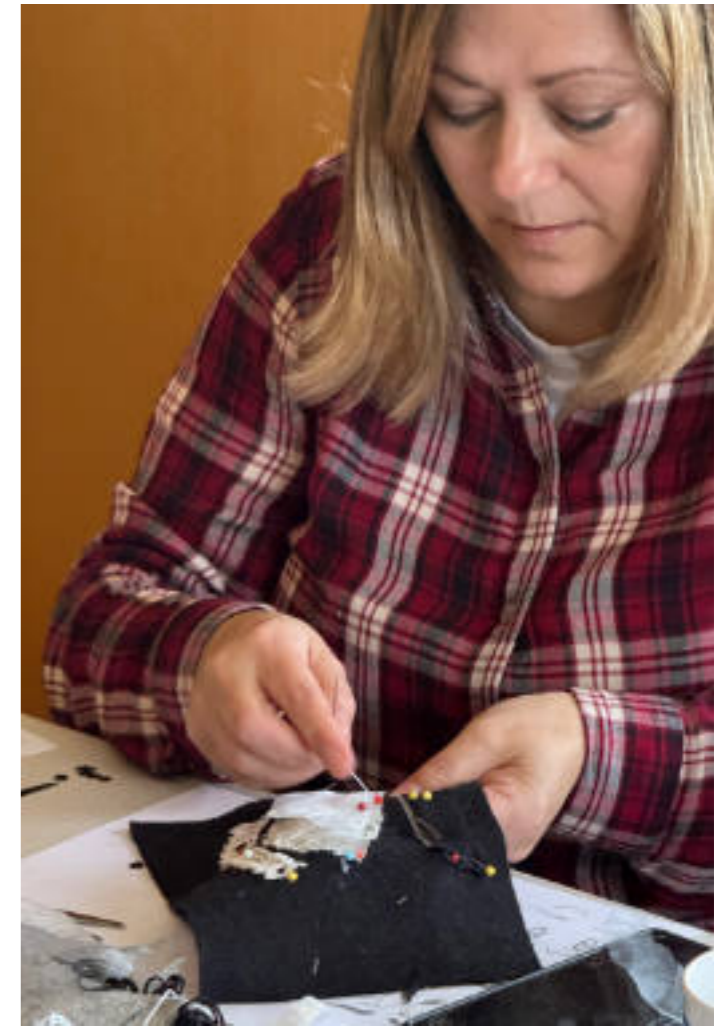
Parent carers often exist in the shadows, seen only in relation to their child’s needs. One mother describes how, during the school run, when her child was having a meltdown, she wished she could ‘wriggle on my belly in and out of the gate and not be seen.’ The judgement, the stares, the feeling of isolation—it is relentless.

Yet, in the safety of this project, they felt seen. They felt heard.

‘Your thoughtful words of kindness made me feel very heard and seen, and I cannot thank you enough for creating this quilt, giving us the opportunity to join in.’

‘We loved taking part in this project. The feedback from parent carers has been incredible.’

‘Thank you for helping me to see me.’



Art as healing and expression

In stitching, drawing, and embroidery, they found a language beyond words. The process became symbolic of their lives—the knots, the unraveling, the frayed edges, the need to cut close to the fabric yet leave space to breathe.

‘I’ve lost so much confidence over the years. Your affirmation and understanding really help. Doing the piece helped me rediscover something I used to enjoy and can do. I’m hanging onto the word ‘freer’.’

For some, the artwork represented deep emotions locked inside:

‘The eye that I have embroidered represents my son’s eye. The chain stitches are my tears of frustration, pain, emotions locked inside—including anger at those who have hurt him over the years.’

‘In this group we usually discuss practical things- today whilst creating, we’ve opened up more. It’s an emotional thing doing this, but we’ve felt safe to open up- we’ve got something for our hands to do, whilst we talk. It’s easier than talking to someone straight on, face-to-face.’

For others, it was about reclaiming a lost part of themselves.

‘This project gives me space to reclaim me. I used to sew before children, but I didn’t know how to return to it. This project is a gift.’

‘I really enjoyed finishing it off at home—in fact, I was reluctant to stop adding sequins as I found the process really absorbing.’

‘The experience of standing and doing a gross motor sketch really freed me up. I decided to use this for my sewn piece.’

‘You asked me about my preferences about my artwork- that simple enquiry, not about one of the children, made me remember the me before children- the creative, imaginative, and artistic dreamer.’

‘I’ve really enjoyed producing this piece and I’m extremely proud of how it turned out.’

‘I encourage creativity for the kids to help them relax- but I don’t do it for myself- this workshop has been amazing.’



[Connect](#) Glossop

The reality of being a parent carer

There is no manual for this life. The highs are indescribably beautiful, the lows unbearable.

‘It’s a grief—a real loss—when you see other children developing in a ‘typical’ way.’

‘I forget to feed myself. Some days, an entire day passes before I realise I haven’t eaten. I’m so focused on their needs, I forget my own.’

‘You know if you adopt there is a likelihood their coming with something. It still surprised me when it started manifesting. She’d had so much love from an early age. It’s a lovely thought that love fixes everything, but she still feels that trauma somewhere in her brain.’

The emotional toll is immense.

‘I’m on antidepressants. Many parent carers are. I had shingles from the pressure of work and home. You keep going until you crash.’

‘The tear is for all the tears of both sadness and happiness that I have shed over many years for all my children.’

Yet, through the exhaustion, there is unwavering love.

‘My eye symbolises that I love my daughter. She loves me. However, I hurt every day.’

‘You don’t raise the kids, they raise us. My child has taught me so much about myself.’

‘You get a different way of thinking raising a disabled child. With my other children, I couldn’t wait for the next stage—crawling, walking—but I had a lot of enjoyment from my daughter. I took every day and enjoyed it.’



Fairplay Chesterfield

Power of connection

Isolation is one of the hardest battles parent carers face. Until they find each other.

‘Coming here has been so good for me. My friends are kind, but unless you’ve lived it, you don’t get it.’

Face to face groups and online communities have become a lifeline.

‘There’s poor provision and poor support. The best thing we can do is find other people that can help, like the people in this group.’

‘Being in a (parent/carer) group, you don’t feel pressure, you don’t feel judged, everyone understands.’

‘There are thousands of families like ours, but we are dotted around, far enough apart not to easily meet. The internet has saved me, connecting me to real friendships with people I’ve never seen below the neck.’

Through these connections, they find strength. They refuse to be diminished.

‘Together, we can grind down expectations and old mindsets, and create a way forward which is positive, inclusive, supportive, and loving.’

The older parent carer and grandparent carer

Caring for a child with disabilities is a lifelong commitment. For some, it continues far beyond what society expects.

‘I still look after my daughter—she’s 63.’
‘You lose quite a few friends, but you gain them too. Their children have all moved on. Ours haven’t, they’re still with us.’

For grandparent carers, the challenges are layered with the exhaustion of age and the weight of responsibility.

‘I’m not a parent carer, I’m a grandmother carer. I took them in as children, and they’ve never left. Everything I have, I’ve had to fight for.’

‘Sometimes I feel like not getting up. I just get up. I do the best I can. And I help other people. Most people don’t realise what carers give up. I’m nearly 71, still fighting for them. She’s got me to support her, but how long is that going to last?’

Even in their own struggles, they continue to look out for others.

(As she talks, she’s constantly looking around—she catches the eye of another person in the group—‘Are you ok?’ she asks.)



The systemic struggle

Parent carers battle not just for their children's needs but against a system that often works against them.

'The hardest thing isn't the caring itself, it's the fight to get support.'

'Teachers need to listen and believe parents. Saying 'She doesn't do that in school' is not helpful.'

Some find themselves seeking their own diagnosis, seeing reflections of their struggles in their children.

'There's a whole generation of women who were missed in diagnosis. They're determined that their children won't be.'

And looming over it all—the fear of the future.

'What's going to happen when I'm not there? That becomes my main mission.'

'It's a constant worry—what's going to happen to your child when something happens to you?'

Holding onto the glimmers

Through the exhaustion, there are moments of pure, unfiltered joy.

'The little things surprise you. Like my big achievement of him going into the garden and NOT pulling off all the flower heads!'

'The purity of his unfiltered smile—that's the beauty others don't see.'

In these moments, parent carers remember why they keep fighting. Why they keep loving. Why they keep going.

'The laughs we've had together. Just being together.'



STEP Trafford Parents Forum

I SEE you

These voices are a testament to the resilience, love, and strength of parent carers.

They reveal the unseen emotional weight, the systemic barriers, and the deep, unwavering commitment they have to their children. They also highlight the power of art, community, and simply being acknowledged.

‘I SEE You—those words mean so much. Carers aren’t always seen or understood.’

‘Sometimes all we need is for others to just listen and not judge.’

And now, through these stories, they are. They are seen.



St Andrew's Junior School, Glossop

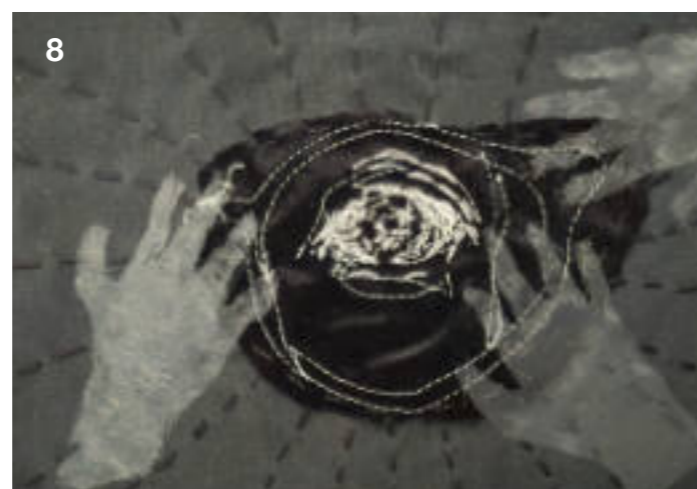
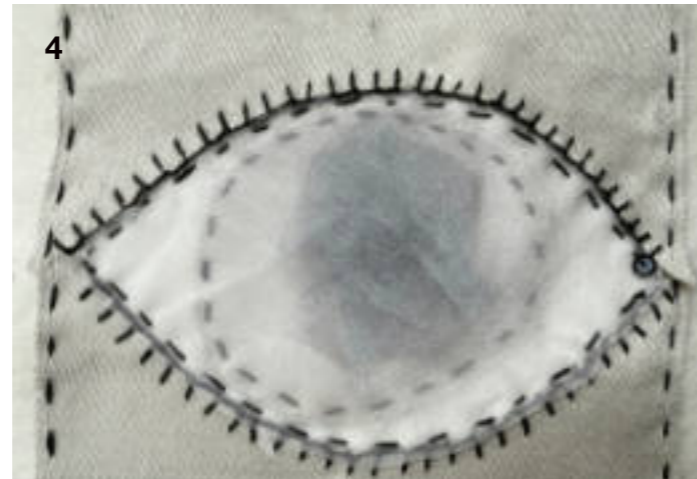
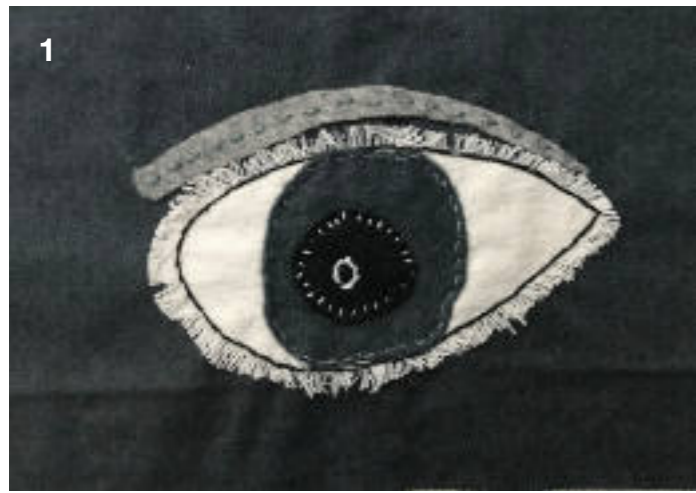


St Andrew's Junior School, Glossop

Opposite: Lifted Manchester



THE EYES



1 Alexandra Thompson
Some text about alex's eyes

3 Alice Bowen-Churchill
'I was glad to have embroidery to channel my feelings.'

5 Allie Peake
'My piece is about being wide awake and alone in the night, looking after a child with a hidden disability.'

7 Alison Ross

9 Amy R

11 Anonymous
'Sleep has always been an issue since he was born, hence the star fabric and zzz's. As much sadness, exhaustion and frustration as I feel, he brings me so much joy, so the tear drops are beautiful as well as poignant.'

2 Alexandra Thompson

4 Alicia

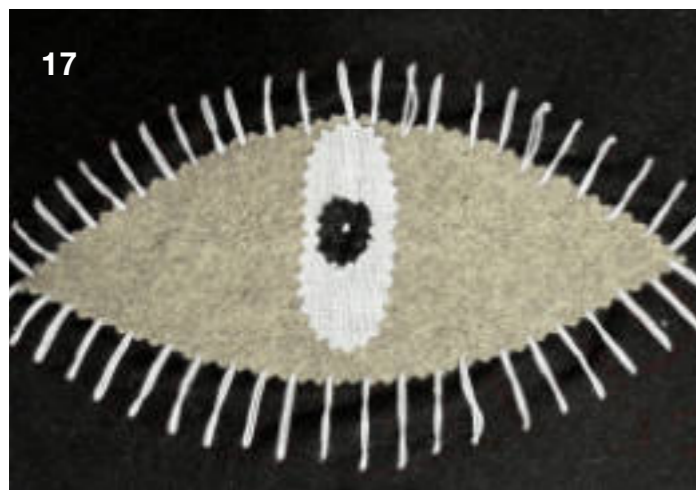
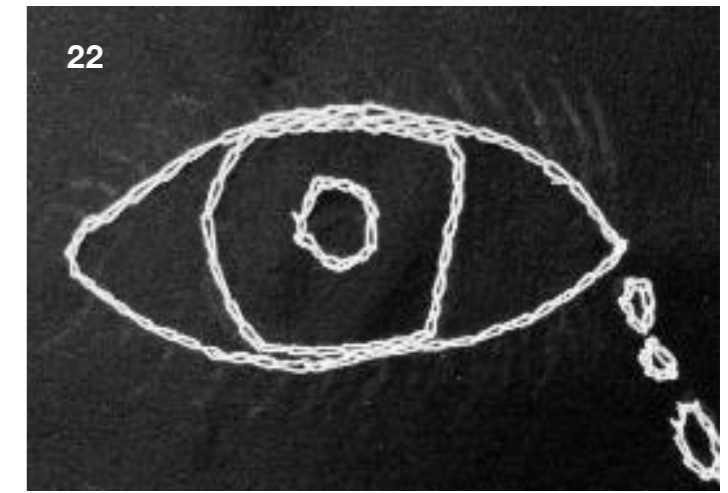
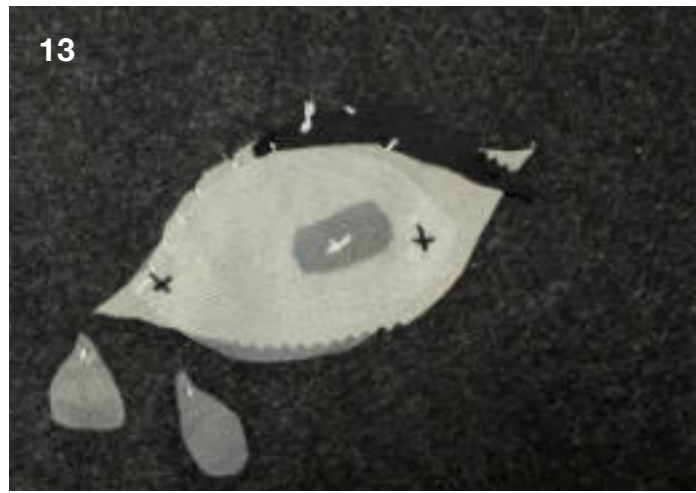
'I've got complex vision, so I can't see very well. Tonal contrast is tricky for me. The layer of fine fabric represents that.'

6 Alisha

8 Amelia De Rougemont

10 Anonymous
Link it to the story in end

12 Becky Hague



13 Bridget

Over the years there's been a lot of tears. Tears they help me. It's been a massive rollercoaster being a SEN parent- the highs are so high, the lows so low.'

15 Charlie Montague

'The crazy wurlwind world of being a parent carer. My eye is my eye at home- in the eye of the storm.'

17 Christine Devlin

19 Claire Housley

21 Dawn Hockey

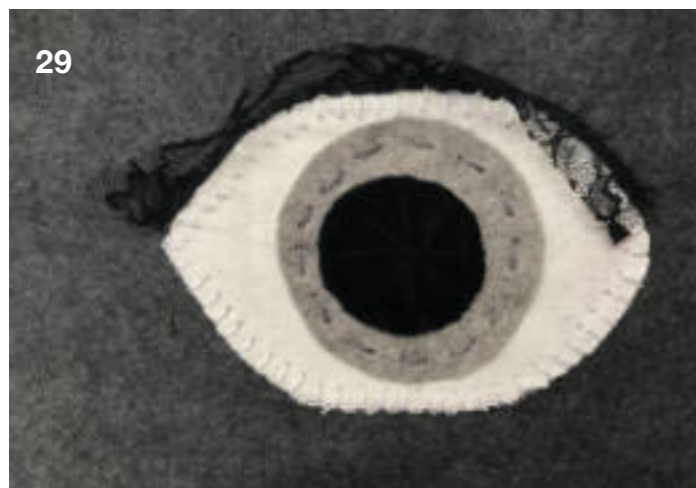
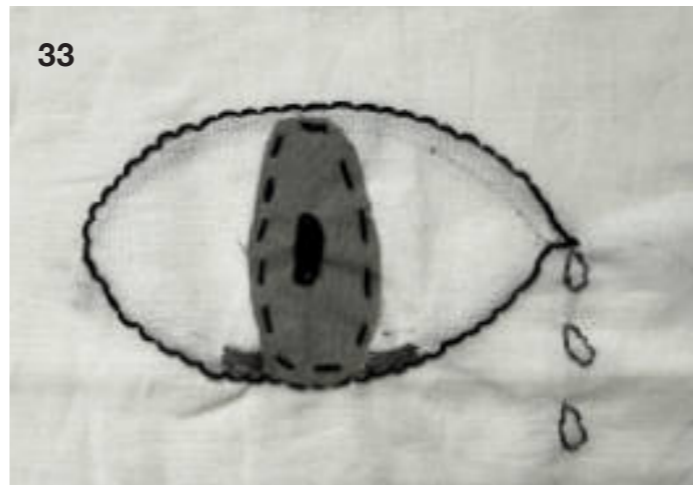
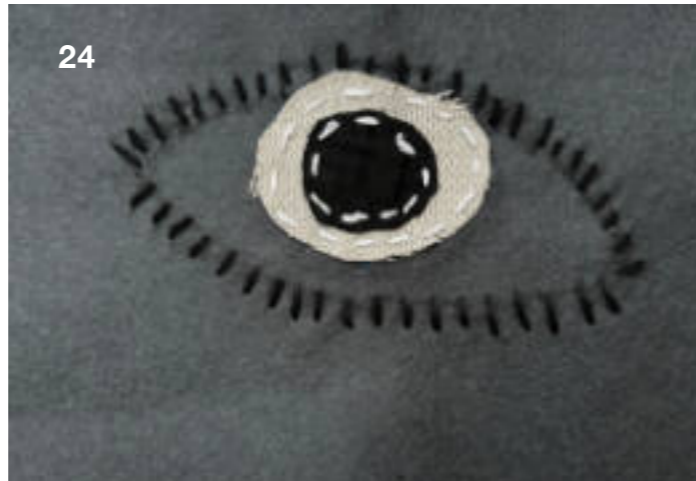
14 Catherine O'Sullivan

16 Christina Kalinowski-Doodle
'The piece represents the need to understand some of the hidden challenges faced by individuals with hidden disabilities. It serves as a reminder to be mindful in recognising that not all struggles are immediately visible.'

18 Claire Domville

20 Clare Duffy
'I made it from layers of fabric, with the appearance of looking through a hole- feeling 'trapped'. I've been so busy, caring, helping, advocating and fighting for my children that I've perhaps lost my own identity and given up on my hopes and dreams. People see Clare the mum- I want to show there are more 'layers' to me.'

22 Denise Dunston



23 Denise Tye

'It's my eye- the lightbulb is about dreams, the stars for my mum and dad. '

25 Elaine

27 Emma Thompson

29 Frances Walker

31 Hayley Aston

'I was finishing off this last night with my son who showed interest in what I was making. He asked me if he could feel it (we are obviously a very sensory family) He pressed it on his face and said "now you have some of my DNA for your project."'

33 Hazel Atherton

'This is based on my child's eye. Life's hard for her. She is seen, but battling all the time. This containment is everything. Fighting all the time.'

24 Eileen Mary Cairns

26 Emily

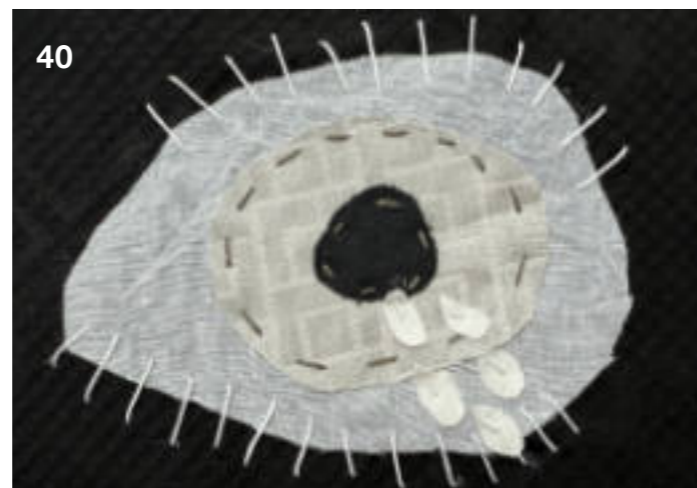
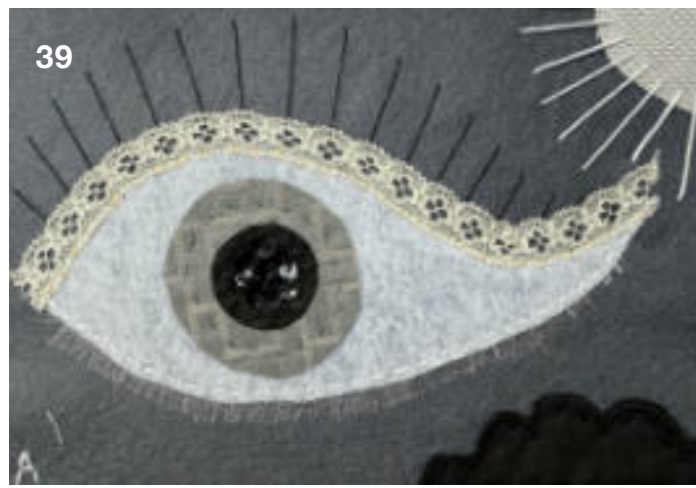
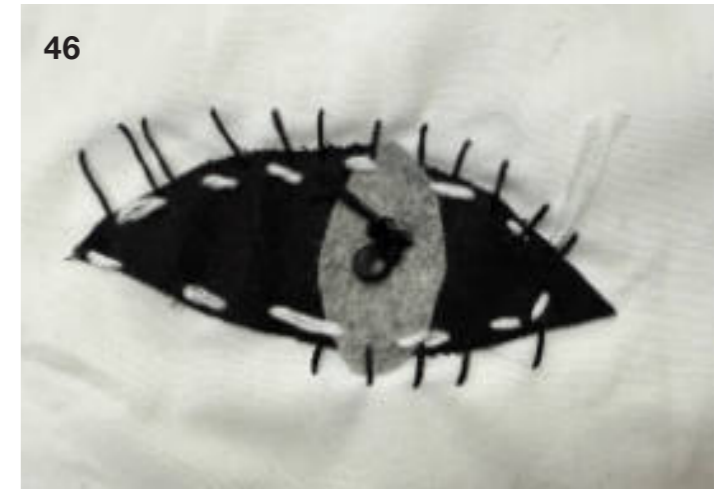
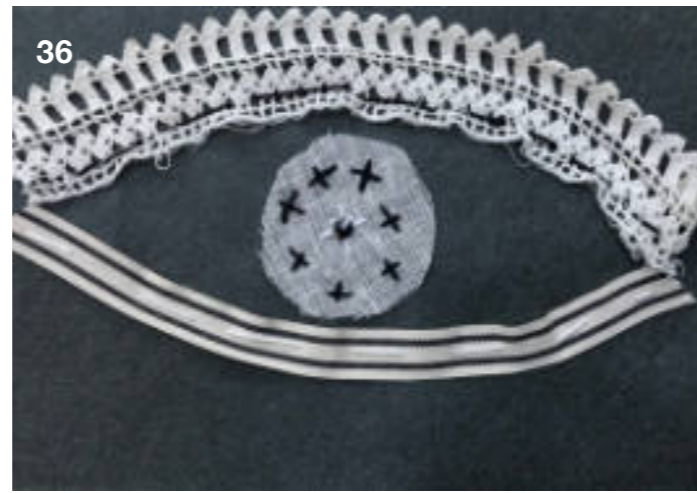
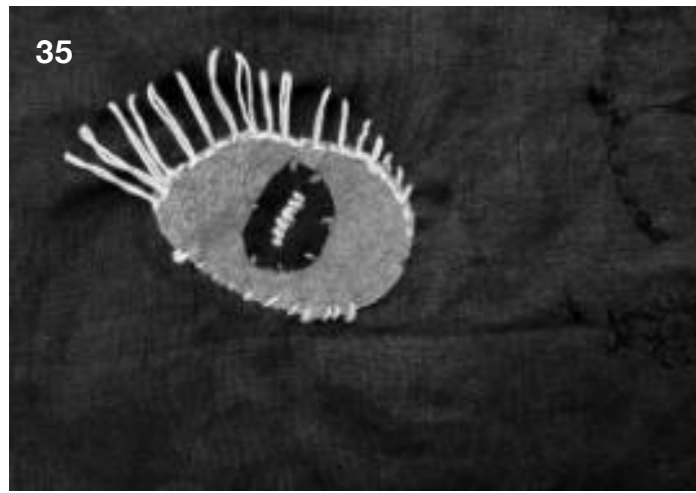
28 Esther Edwards

30 Gill Thompson

32 Hayley Moorcroft

34 Heather

'I've tried to keep my eye calm. Totally calm. It's what I need in life. I've cut out the tears- I don't want to cry any more. If I do, I might not stop.'



35 Helen

37 Holly Robson

39 Jayne Leverett

'We often feel like we're living on a different planet to other people/ families, suspended in the sky somewhat disassociated from others. Often shadowed by dark clouds- fear, stress, pressure, the unknown. But also experience joy and true moments of light unlike others too.'

41 Jeanette Savage

43 Jenna Miller

'As a mother of neurodivergent children, I strive to stay true to myself, whilst navigating the challenges of their struggles.'

45 Jenny Adlem

36 Helen Holmes

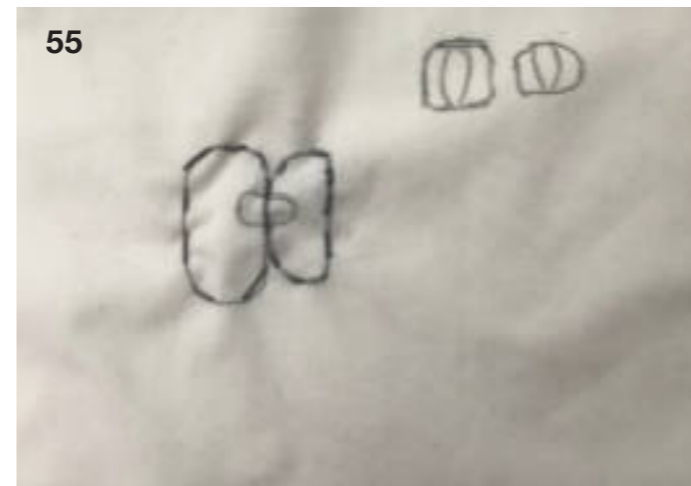
38 Janet Downs

40 Jean McCormack

42 Jen

44 Jenny

46 Jo Threlfall



47 Jo Walsh

'My daughter has 3 non-visible disabilities- I chose a fragile fabric with a wavy spine to represent Hyper-mobility Syndrome. Soft textures are so important to autistic people with heightened sensitivity. A piece of gossamer covers the eye to represent Irlens Syndrome.'

49 Julie Pye

51 Kate
'I'm not a creative person- I'd love to know what's going on inside his mind- so the keyhole is trying to represent what's going on. That chaos behind his eyes.'

53 Kelly Wagg

'Please see me- I'm here. The eye is meant to be a window to the soul. People don't know the struggles you deal with everyday.'

55 Kevin Wright

48 Julie Leach

'Mine is a multi-layered cloud. Some of it is fraying, some pretty- because there is so much going on- and no one can tell what's happening behind the eyes. Sometimes I feel like a massive cloud, ready to burst'

50 Karen

52 Katie Burman

'The newspaper cutting (in the embroidery) is from an article about miss-diagnosed children with hearing difficulties- which felt relevant.'

54 Kerry Barrows

56 Kirsty



57



58



65



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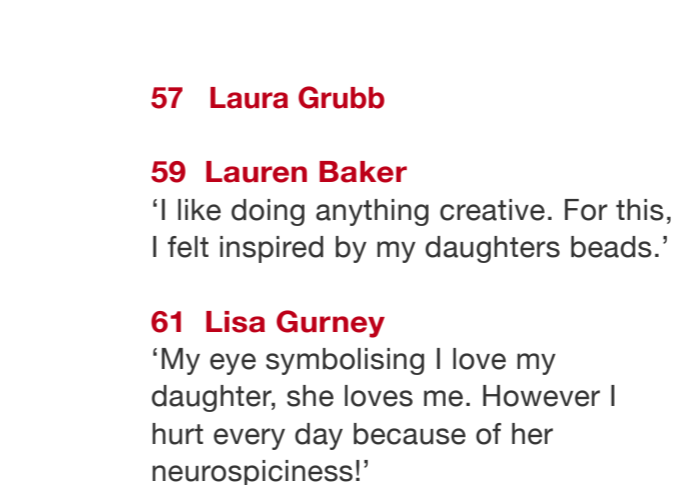
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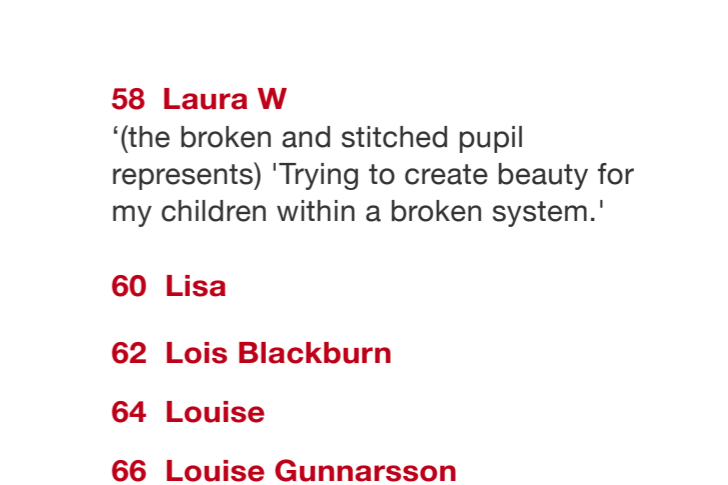
61



62



63



64



63



64

57 Laura Grubb

59 Lauren Baker

'I like doing anything creative. For this, I felt inspired by my daughters beads.'

61 Lisa Gurney

'My eye symbolising I love my daughter, she loves me. However I hurt every day because of her neurospiciness!'

63 Lois Blackburn

65 Louise Greenwood

'The veins represent the pain I experience from possible Fibromyalgia. The lashes are big and glamorous, to represent the 'mask' that make up provides. I say to myself "Get your makeup on and get to work, ignore the pain." I can do this to a certain extent, but often burn out.'

67 Lucy Barnes

58 Laura W

'(the broken and stitched pupil represents) 'Trying to create beauty for my children within a broken system.'

60 Lisa

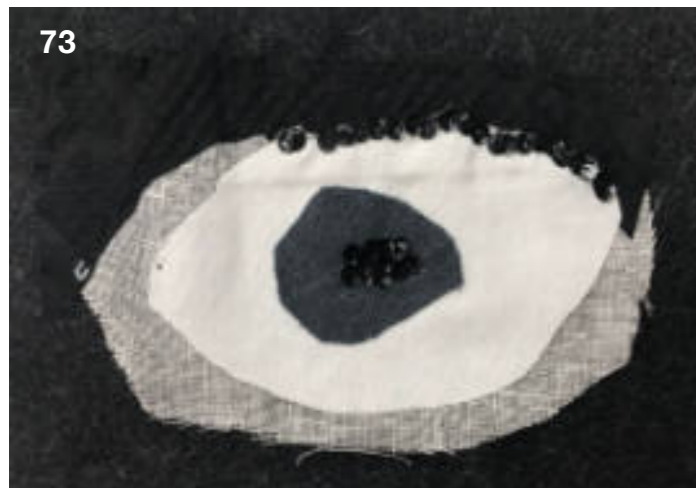
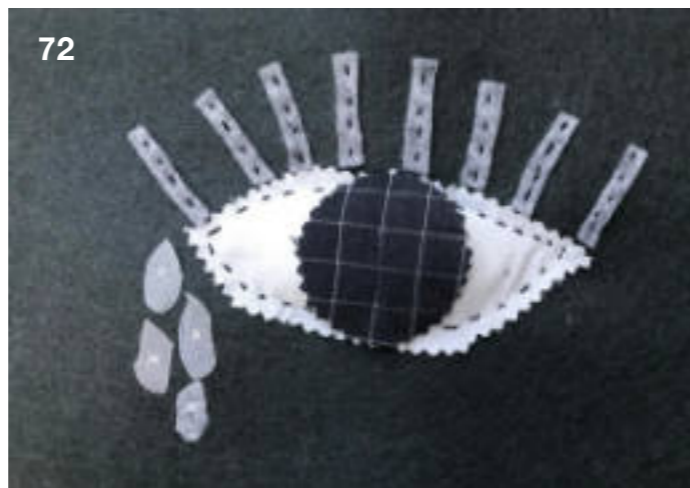
62 Lois Blackburn

64 Louise

66 Louise Gunnarsson

68 Lucy Mills

'It's so lonely and everything is a battle. You sometimes get small wins which give you moments of joy, but then you move onto the next battle. It's relentless and exhausting.'



69 Lucy Porter

'The eye shows the neurodivergent wheel, with its spiky profile. ND is prevalent in our house, as we discover more about our son, we also discover more about ourselves. It's a journey that has many peaks and troughs. It feels relentless, but we keep fighting for what our son needs.'

71 Maria Moore

73 Melissa Ebbatson

75 Morenike Artist

77 Nina Fedorski

78 Olivia Jayne Dunston

70 Margaret Smith

72 Maxine Proize

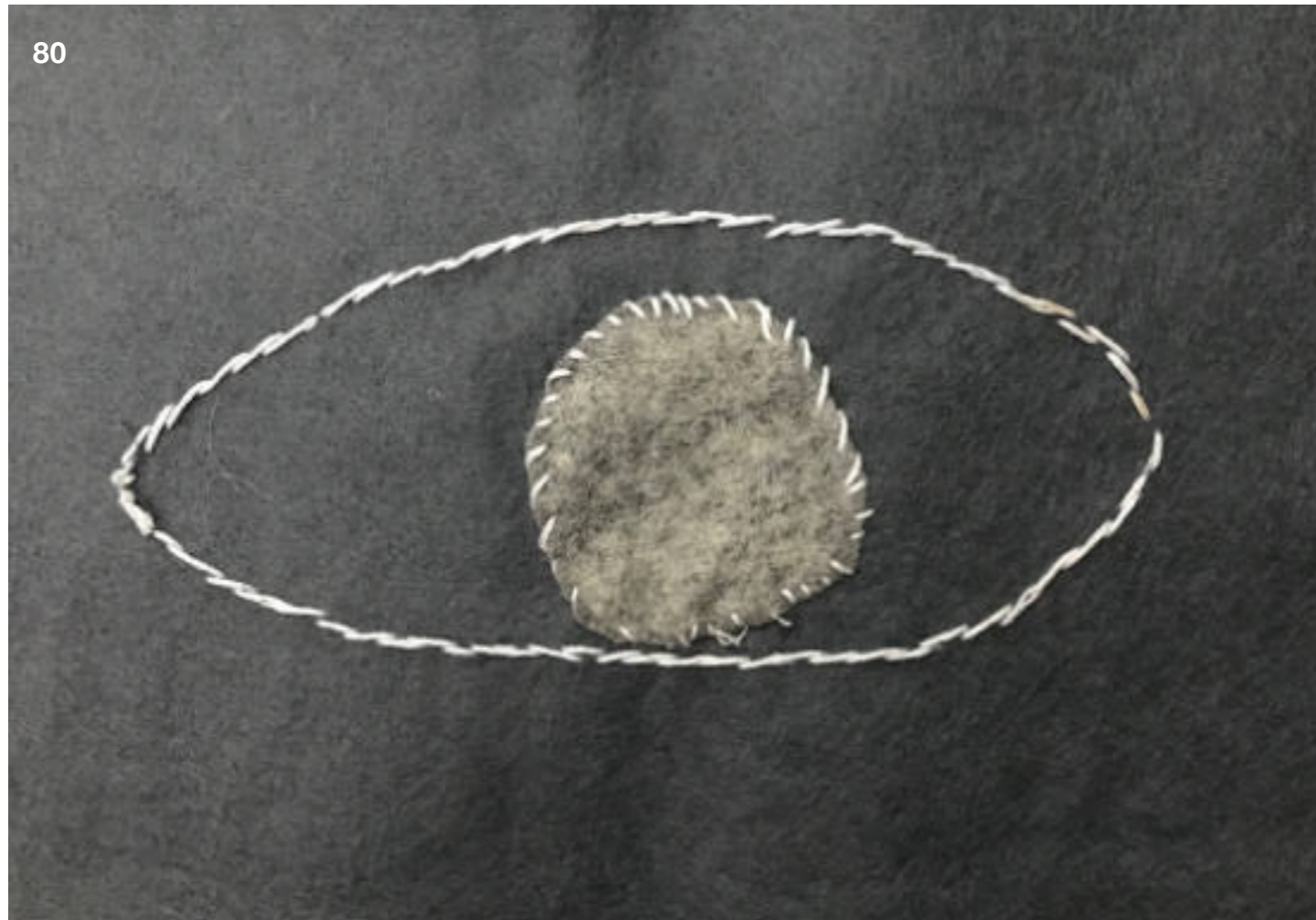
'With my 2 beautiful neurodiverse girls my eyes are always wide open!! The checked cloth represents the barriers they've had to overcome and will continue to do so. 4 teardrops one each of my family as we have battled with the frustrations life has thrown at us, and a simple kiss to each to show how much love we have.'

74 Michael Hockey

'My eye is open because people need to see. The blank background reminds us to look beyond the obvious. The pupil and iris use a material I can't stand touching—symbolising the discomfort needed for true understanding. Fraying edges reflect families under strain, held together by the stitching—support.'

76 Nikki

79 Orla Conder



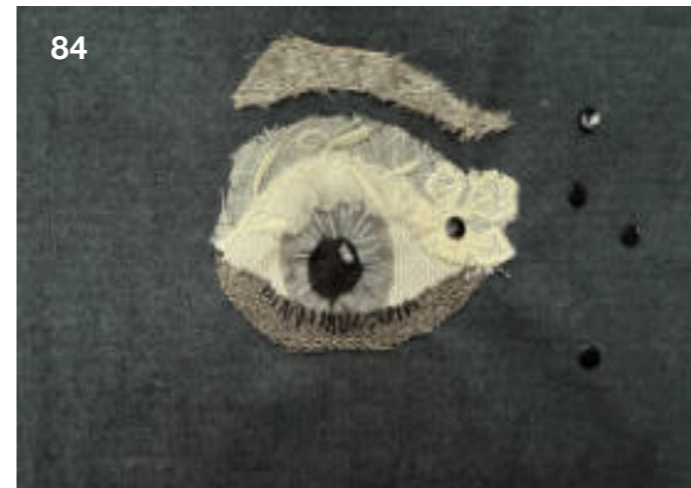
80



82



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81

80 Pam

82 Pauline Ferrick- Squibb

84 Penny Challinor

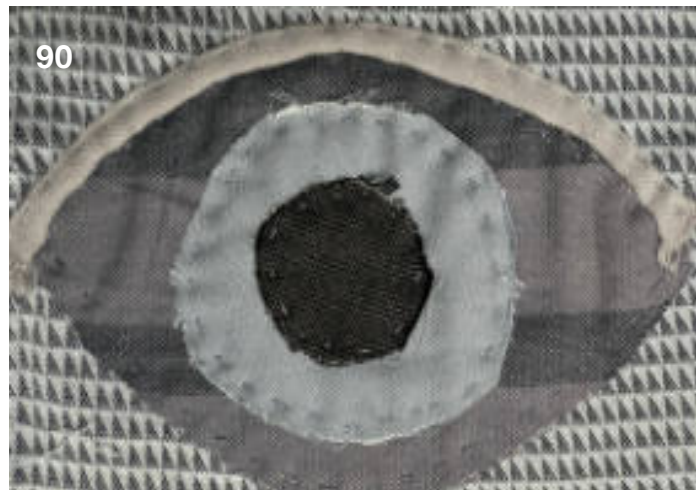
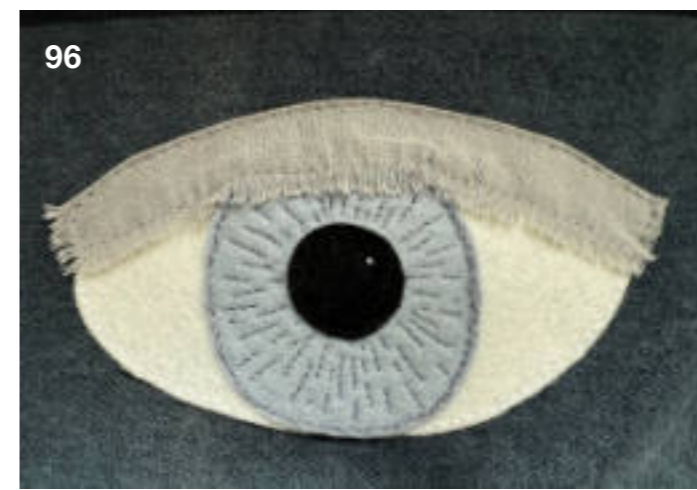
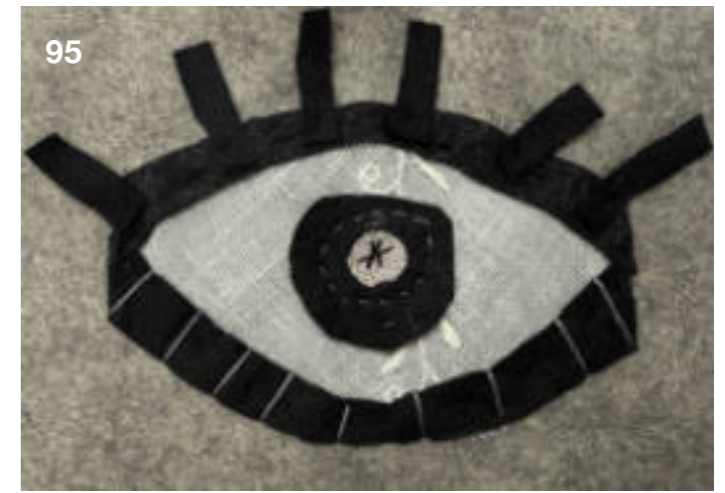
81 Patricia Sales

83 Pauline Johnston

85 Rachel

'God says to me
'I see you'.....'

In that moment, I know
He sees my heart
He sees into my soul
He loves me
I am not alone...'



86 Rachel Dye

88 Rachel Jackson

'It is made using material from one of my sons t-shirts making it even more meaningful.'

90 Rachel Yuen

'Constant Vigilance. I often feel unseen yet remain on high alert, being vigilant in a world that misunderstands my son's needs and behaviours. As I stitched the eye, I reflected on the energy it takes to ensure he feels seen, safe, and his needs met.'

92 Rebecca

94 Rebecca Wilde

'The dark represents the dark times. But there's lots of beauty to- the flowers are for her- people don't always see the beauty.'

96 Sam

87 Rachel Dye

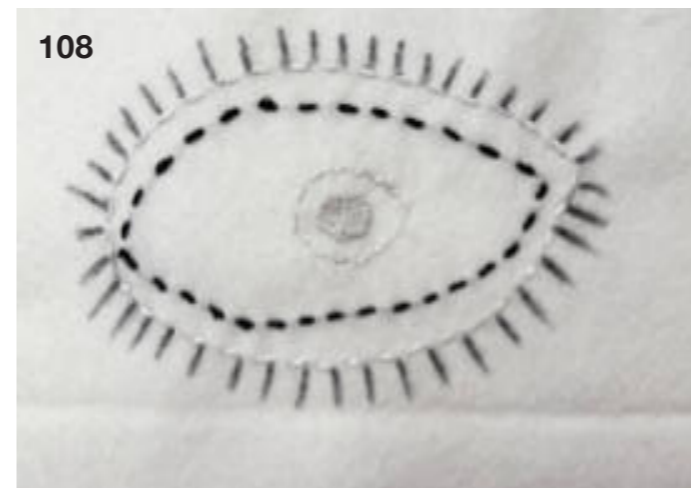
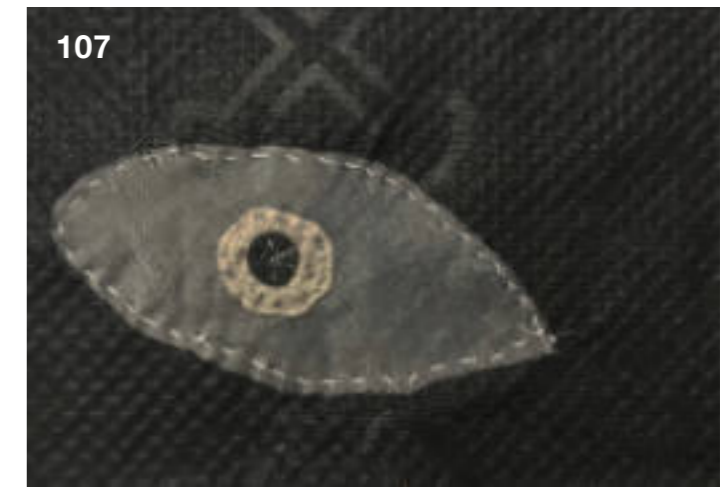
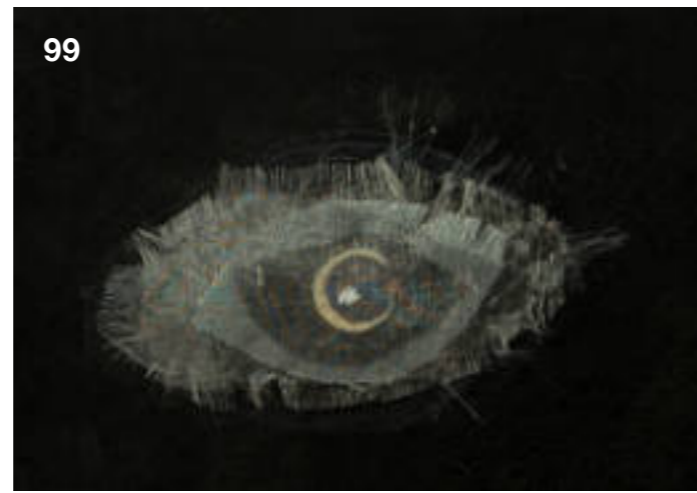
89 Rachel Oxer

91 Reb Burt

93 Rebecca

95 Saima Rizwan

97 Sam



98 Sam Poole

'My glasses are split in half, one side for me, one for my dad. I wanted to represent my dad for all we went through together, and all the support he gave me.'

100 Sara Scott-Rivers

102 Sarah

'The dark represents the dark times. But there's lots of beauty to- the flowers are for her- people don't always see the beauty.'

104 Sarah B

106 Sarah Tweats

108 Sharon Gallagher

99 Sammy Crilly

'I want to name it 'The Veil'. The veil that you're seen though or not. We also use a veil as protection- for ourselves or for others. I've done it the blacks, lots of shadows. I've embraced imperfection for this in making it, celebrating 'Fuck it.''

101 Sarah

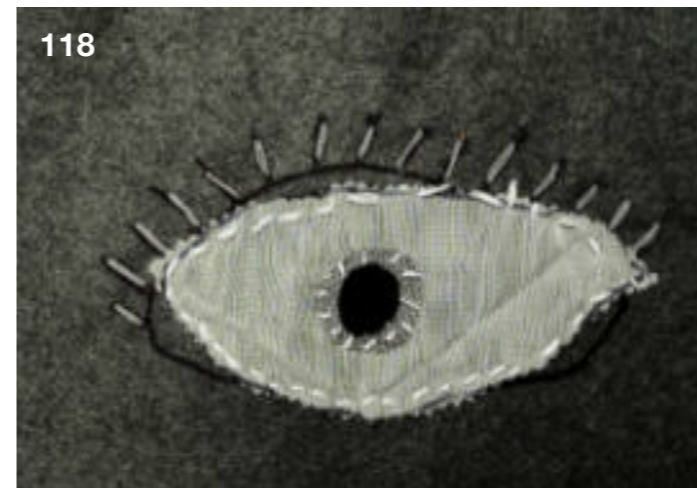
'It is made using material from one of my sons t-shirts making it even more meaningful.'

103 Sarah

105 Sarah Fowler

107 Sarah-Jane

109 Sherie Rogers



110 Sonia McDonagh

112 Sophie Anderson

102 Sarah
'The dark represents the dark times. But there's lots of beauty to- the flowers are for her- people don't always see the beauty.'

114 Sue

116 Tabina

118 Terry

111 Sophie

'I felt it was really important to choose one of my kids' eye doodles - (to base my embroidery on). The eye wasn't looking directly at us, because that would never happen.'

113 Stephanie Aitken

'I've created a heart in the centre of my eye, for my children. I can see them, when other people can't.'

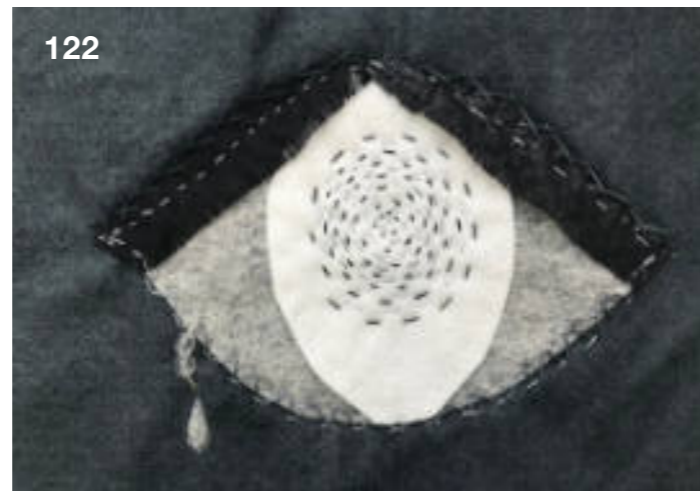
115 Sue Jane

117 Tamsin Grainger

'I hope they aren't too startling- they are my own eyes! It took a long time to stitch, trying to get it to look the way I wanted, and I'm not sure I really managed it. I enjoyed the process overall and was pleased to have the prompt.'

119 Tracey Comrie

'Eye= I
I spent my time re-discovering myself through a lost creativity of embroidery. Art is very powerful and connects with so much of our inner life without realising.'



120 Tracy Newton

121 Trish
'I've created a heart in the centre of my eye, for my children. I can see them, when other people can't.'

122 Vic

Opposite:
Talbot House Manchester

Beyond the pages:

Creative ways to engage with I SEE you

The I SEE You project is not just about viewing art—it's about starting conversations, fostering empathy, and making the invisible, visible. After exploring this catalogue, we invite you to continue the journey by engaging in creative activities that deepen understanding and build connections.

Whether through writing, stitching, or community action, these ideas offer ways to reflect on the themes of the project and contribute to a more inclusive world. Each activity is an opportunity to see, listen, and create in response to the experiences shared in I SEE You.

1

Invisible Stories: Writing exercise

Write a short story, poem, or diary entry inspired by the themes of the project. Reflect on a time you felt unseen, imagine life from the perspective of a parent carer, or explore what visibility means to you.

2

Conversation starter cards

Create a set of conversation prompts for friends, family, or community groups, focusing on non-visible disabilities, caregiving, and inclusion. These discussions help break down stigma and encourage understanding.

3

Threading conversations: Stitch & share

Host or join a stitching group where people can embroider while discussing themes from I SEE You. This can be a space for parent carers, allies, and creatives to connect and share stories in a relaxed, supportive setting.

4

Letter to a carer

Write a heartfelt letter (real or anonymous) to a parent carer, expressing appreciation, solidarity, or encouragement. These could be shared through local support groups or online initiatives.

5

Mending the gaps: Textile art for awareness

Take a piece of fabric or clothing with a small tear and use visible mending techniques—decorative stitching that highlights rather than hides the repair. This symbolises the unseen struggles of parent carers and the beauty in acknowledging, rather than ignoring, challenges.

I'd love to see what you create or hear about the conversations this project has sparked. Please share on Socials using the #ISEEyouproject and tag me in:

- Instagram [@artistloisb](#)
- Facebook [@ladyloisartist](#)

About me:

Lois Blackburn

For over 25 years, I have been creating art that explores deeply personal and often hidden subjects, including loss, grief, health issues, and body image.

My work seeks to provide comfort, encourage reflection, and celebrate resilience. Through collaboration, I aim to create spaces where individuals can share their experiences, find solace, and gain new perspectives.

Using mediums such as batik, quilts, and embroidery, I have worked with diverse communities, from individuals experiencing homelessness to older adults, to produce meaningful and socially engaged art.

In 2006, I co-founded the Community Interest Company **arthur+martha**, where I served as Director and lead artist until 2021. This organisation brought together people from varied backgrounds to create art that gave voice to underrepresented stories and experiences.

One of my recent projects, **Comfort**, involved 180 women and teens, including non-binary and trans individuals, in the creation of a large embroidered quilt. Each contributor shared their personal stories and artwork on the theme of breasts, covering a range of experiences from puberty to

ageing, from illness to pleasure. Exhibited across the UK, this quilt has become a powerful testament to shared experiences and self-expression.

I SEE You, has been a deeply moving collaboration with parent/carers of children and young people with non-visible disabilities. This initiative has offered a space for creative engagement, relaxation, and self-care, enabling participants to share their stories, hopes, fears, and advice through artistic expression.

Thank you for being part of this experience.

To learn more about my projects, visit

<https://loisblackburnartist.uk>

and follow me at:

- Instagram [@artistloisb](#)
- Facebook [@ladyloisartist](#)





Thank you

As I SEE You comes to life, I want to take a moment to express my deepest gratitude to everyone who has made this project possible.

To the incredible parent carers who shared their stories, experiences, and emotions—thank you for your trust, honesty, and courage. Your voices are at the heart of this project, bringing visibility to the unseen and recognition to the often-overlooked reality of caring for children with non-visible disabilities.

To the support groups, organisations, crowdfunders and individuals who have supported I SEE You—your belief in this work has been invaluable. Whether through hosting workshops & exhibitions, funding, collaboration, guidance, or encouragement, each of you has played a vital role in making this project a reality.

To the parent carers who have contributed their time and talents—in stitch and words, your sensitivity and skill have helped translate lived experiences into powerful artistic expressions.

And finally, to everyone who has engaged with I SEE You, whether by attending events, sharing the project, or simply taking a moment to listen—thank you. Acknowledgement is powerful, and your willingness to see, hear, and understand means more than words can say.

This project is a testament to the strength of community, the importance of being seen, and the power of storytelling. I am truly grateful.

Groups

Autism East Midlands <https://www.autismeastmidlands.org.uk/>
Carers Connecting SEN High Peak <https://brickcornercafe.co.uk/>
Castle Hill High School <https://www.castlehill.stockport.sch.uk/>
Connect, Glossop <https://www.facebook.com/Connectglossop/>
Derbyshire Parent Carer Voice <https://derbyshireparentforums.co.uk/>
Diabetes Midlands <https://www.diabetes.org.uk/support-for-you/diabetes-uk-in-your-area/midlands-and-east-of-england>
Diabetes Sheffield <https://www.sheffielddiabetesuk.group/>
Epilepsy Action <https://www.epilepsy.org.uk/>
Fairplay <https://fair-play.co.uk/>
Genetic Alliance UK <https://geneticalliance.org.uk/>
George Marshall Medical Museum, Worcester <https://medicalmuseum.org.uk/georgemarshallmuseum>
Level Centre Derbyshire <https://levelcentre.com/>
Lifted MCR Wythenshawe <https://liftedmcr.org.uk/>
PIP-UK Poland Syndrome Support <https://pip-uk.org/>
Rare Disease <https://geneticalliance.org.uk/campaigns-and-research/rare-disease-uk/>
RNIB <https://www.rnib.org.uk>
Sam Hickman
St Andrew's CofE Junior School, Glossop <https://www.standrewshadfield.org>
Talbot House, Manchester <https://www.talbot-house.org.uk>
Tourette's Action <https://www.tourettes-action.org.uk>
Trafford Parents Forum <https://www.traffordparentsforum.com>
UMBRELLA <https://umbrella.uk.net>
Zink, Neuro Diversity Hub <https://zink.org.uk>

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**ARTS COUNCIL
ENGLAND**

APPENDIX

Experiences
and poems

In our own words

92-92	ADHD and me	Lois Blackburn
94-95	Creativity as a way of being	Sophie and Lois
96-97	Dissociative Identity Disorder	Anonyomous
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100-101	Here in the Unravelling	Sophie
102-103	Labels	Shantelle Barrowes-Bayewunmi
104-105	The gift and the grief	Sarah
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ADHD and me

Lois Blackburn

I always knew I was a bit ‘different,’ struggling to fit in socially and academically. As a child, I spoke gobbledegook until speech therapy helped ‘slow me down.’ In my teens, a dyslexia diagnosis explained my difficulties with maths, spelling, reading, organisation, and memory. But something still didn’t quite fit. I called it having an "arty brain" — art kept me steady, gave me focus, and became my escape.

Starting Art Foundation was a revelation. Finally, I was surrounded by like-minded people, creating all day. **I’m lucky to have built a career in the arts, a world where creativity, variety, and a bit of chaos are embraced.** I doubt I could survive in an office, sitting still every day.

Through the I SEE You project, I’ve reflected on my experiences. Neurodivergence runs in my family — my dad is clearly on the autism spectrum, and my kids hinted that I might be too, but it didn't quite fit. Then, my daughter casually mentioned that ADHD presents differently in girls. I started reading... and suddenly, it all made sense.

I had always pictured ADHD as hyperactive boys bouncing off classroom walls, but I ticked nearly every box for girls and women with it. For 55 years, I’ve found ways to manage it, masking my struggles in the arts, where my quirks are just "being creative."

The I SEE You quilt includes work from parent carers of children with non-visible disabilities, mostly neurodivergent children. Many parents I met were either diagnosed themselves, on the pathway, or noticing traits in their children

that mirrored their own. Greater awareness brings self-understanding, better coping strategies, and, hopefully, less stigma. I’m still at the start of this journey, but it’s liberating to finally understand myself.

I burn out after too much socialising or focus. My mind is a whirlwind of relentless thoughts. I’m emotional, impulsive, and often put my foot in my mouth — saying things before I think, then spending restless nights worrying. I’m messy, disorganised, clumsy, always losing things, and struggle with structure. I hyper-focus, but find it hard to concentrate when people talk. I fidget in anything formal, filling pages with doodles. Sleep is elusive, and my brain never switches off. Relaxing? Only with a distraction — books, TV, or a walk. Anxiety lingers, decisions are tough, and my thoughts constantly jump.

But there are strengths too! My hyper-focus is a gift when channelled into the right things. I struggle to finish tasks but thrive on creative ideas. Despite my impulsivity, my intuition and empathy help in my work. I’m great in a crisis, love problem-solving, and enjoy deep, fast-moving conversations. My brain may be chaotic, but it’s highly creative, seeing patterns and connections others might miss.

I’ve found ways to manage, but it still can negatively impact me and those around me. Hopefully, understanding myself better will quiet the shame and embarrassment. I feel like I’m masking less — finally embracing what makes me me.

Art has saved me, as have the people who accept me for who I am. I’d love to hear — what has saved you? Now, what’s next?

First, I just need to find that list... I do love a list.

Creativity as a way of being

Sophie and Lois in conversation (extract)

Creativity isn't just about making art—it's a way of thinking and coping. In this conversation, Sophie and Lois explore how creativity helps them navigate parenting, neurodivergence, and life's challenges. From daily routines to moments of crisis, they show how creativity can bring resilience, connection, and even a little magic.

Sophie: 'I reckon in my life, if everything feels like a bit of drudgery and hard work, it's because I'm not being creative.'

If I can, I can keep in a creative mindset all day, even if it's just for me. It's an attitude of mind. If I'm lucky I get to use my hands and sit down and make or create something, but if I'm not, then it's about how I go about my day. I'm still in a position where I'm serving my 17-year-old 3 meals a day in their bedroom! That means my day can be full of drudgery, or it can be full of creativity and love. **That's what creativity does for me. It means I can cope through the worst days. It's like magic. It's the thing that brings daily, minute by minute magic.**

I just have to flick that switch that reminds me there's a choice here. I can think about it in this creative way, or I could get really bogged down. And I've spent plenty of years being bogged down.

It's a choice between habitual behaviour or creative behaviour for me... so when everything feels a bit habitual, just give me a little sprinkle of creativity!

Sophie: What about you?

Lois: 'Creativity, it's a lifesaver. And it's something I've always done. It's something that I don't always do enough of- the actual making, because I spend too long on blinking forms, admin and trying to get the funding for projects ...'

We're probably aren't even aware we are creative thinkers all the time. It's about embracing and redefining creativity.

I'm dyslexic, and I think that it's one of the things they say is a the bonus- creative thinking. I know that at times of stress and anxiety and when times that have been really, really hard. It's really played a part in keeping me going.

I also feel that the educator / facilitator in me, is really, really important as well. Because at times in your life, when you can feel so useless in many ways. When I work with someone, supporting and encouraging their creativity- there's no better gift I can give. It's a real drive. It is absolutely, fundamentally part of my life.'

Sophie: 'Creativity should happen in every lesson, at school, it should be infused through the whole of school. Celebrating creativity as a way of being as opposed to creativity as a thing we do.'

As a parent to special needs kids, I think that's been the distinction for me. I might not have time to make anything any more. I might not have time for my own creative practice. But I am making 3 meals a day, and finding ways to engage with my kids. There is creativity, in my life the whole time.

Dissociative Identity Disorder (DID)

Anonymous

Our adopted 26-year-old adult son came to live with me and my husband as a 10 month old foster child. His birth-parents rights were removed at birth because he was exposed to heroin. Those first 10 months of his precious lives were not optimal and he experienced some very frightening pre-verbal traumas that caused him to have the mental illness of Dissociative Identity Disorder (DID for short.)

This illness used to be called Multiple Personality Disorder and is highly misunderstood and misdiagnosed. DID is caused by severe childhood trauma and allows victims to dissociate from the often life-threatening experience(s) they cannot physically remove themselves from.

The main symptom of DID includes the presence of two or more distinct identities or personality states, each with its own pattern of perceiving and interacting with the environment.

It was the survival mechanism that serve the purpose for our son that has caused immense difficulties in his young life. Early school was difficult for him, so we had him tested at age 8 for the usual suspects, but he was never on the spectrum of anything testable. He started seeing a paediatric psychiatrist at age 13, because schoolwork continued to be difficult, and even that professional doctor couldn't find anything diagnosable.

Besides the school issue, the only other visible symptoms were occasional moodiness, gaps in memory and daydreaming. Sadly, as he aged, substance-abuse has become an issue that he is also working to overcome.

It wasn't until puberty that he himself became aware of what he was experiencing, and then it took many more years for him to be able to understand and feel that he could advocate for help.

After he turned 18, we found him another talk therapist to support him and finally she was able to diagnose him with DID. He is still in therapy and continues to learn how to cope with life and his disease. However, because of social stigma around the DID and because he has been ridiculed in public, he carries shame and is very private about it.

He is smart, hard-working and charming young man who lives independently in a supportive environment and has many solid friends. His current roommate is non-binary and they both joke that each prefers the pronouns 'they/them' but for very different reasons.

As is typical with most parents, our son gave us much joy and much heartache as we tried to raise him right. And as typical with most people, he is a lovely and flawed human and we will always and forever love him.

Dyslexia

Anonymous

Our son formed words much later than other children. He was our first child so we didn't have anything to compare him to; his nursery wanted to run tests on him, he was taken for a hearing test and to see a speech therapist; his hearing was fine. At primary school during the parents evenings I was astonished at the writing ability of the other children who wrote complete stories, whilst our son struggled to write his name.

The SEN at school wanted to run tests, he was sent to a clinic to test for Dyspraxia and was given a set of exercises that he had to perform daily to strengthen his muscles. At those first parents evenings where we all looked at our children's work together, I would sometimes have to hold back the tears wondering why our son wasn't able to read and write like the other children.

His birth had been difficult, and I searched for reasons for his learning difficulties. Every parent wants a happy, healthy child, looking back he was both happy and healthy.

In middle school he was tested again and was awarded an Educational Health Care Plan, he was 12 and had the reading ability of a six-year-old, but the comprehension of a 16-year-old. I knew he was bright, but he would need help evidencing his intelligence in an educational system reliant on reading and writing.

We are now very lucky to have a happy healthy young adult, who has created his own strategies to overcome his dyslexia, word finding difficulties and processing issues. He is intelligent and creative.

He is still reticent about letting people know he has dyslexia. I think about his dyslexia in a more positive light now as it has given him the ability to creatively solve problems in unusual and creative ways.

Here in the Unravelling

Sophie

It's been quite a journey, these past 18 years.

I thought I'd be a good parent. Fun. Thoughtful. Creative.

I am all those things.

I thought we would have loads of adventures together and the explorers of the world.

We have been explorers. Just not of the world, or in the way I thought we would be exploring.

I thought I'd find parenting easy, full of joy.

I thought I'd make lifelong friends and be surrounded by other families, other parents.

It's been the loneliest journey. I could've imagined.

I Imagined you at school, surrounded by success (in the way, I understood it then), followed by university, jobs, relationships.

I couldn't have been more wrong. And I understand success differently now.

It never occurred to me that a childhood could look any different from how I had imagined it.

I wonder how many thousands of us there are, stuck in our own homes, living life differently from how we'd hoped it would be? Little beacons of hope, shining out.

Those early years were just SO HARD, for all of us.

Nothing worked for you.

Food seem to explode your insides. Mealtimes were terrifying.

Friendships were fraught.

School was hit and miss.

You were sensitive to everything and everyone.

It was easier to stay at home. Not to see anyone else.

No one imagined there was anything really wrong.

They just assumed I was doing something wrong.

That you were just very 'sensitive'.

And then Covid hit and everything unravelled.

That was messy.

Now we live in that unravelling.

I like it better here.

We all do.

Here there are no demands, no expectations.

We have ALL been de-institutionalised.

You're thriving now. I have no idea what the future looks like, because futures I've shown before don't look like this.

You have none of the things were told are 'required' to succeed in the world, but I know that will make it work.

It might take us 10 times longer than anyone else, but you'll get there, wherever 'there' is.

You have the most beautiful soul. You have so much to offer the world, if they'll ever let you in.

I hope they do.

Meanwhile, we'll make it work, here in the unravelling.

I love you.

Beyond labels

Shantelle Barrowes-Bayewunmi
Hypnotherapist & Emotional well-being coach

When we, as parents, reinforce unconscious biases or internalised ableist beliefs—such as saying, "My child doesn't have 'bad' autism"—we create a polarising dynamic. This deepens stigma and undermines a child's ability to advocate for their own experience.

It's not for us to decide the extent to which a child's autism or neurodiversity affects them. Their experience is personal, and they alone can determine how their condition impacts them. If a child feels overwhelmed by their autism or neurodiversity, we cannot dismiss it as "not bad" or label their responses as "bad behaviour." Doing so projects uninformed perceptions of disability onto them.

Children and individuals should define what their disability means to them. Co-morbidities play a key role, as multiple interrelated conditions can amplify symptoms. It's essential to consider these not only separately but also in how they interact as a whole, ensuring accommodations suit the child's specific needs.

Labels like "high functioning" and "low functioning" contribute to this unhelpful good/bad divide. A child may function well one day or in specific situations but struggle the next. This overlooks dynamic disability, where symptoms fluctuate due to triggers or throughout the day. Labelling a child in fixed terms can shape expectations and limit the flexibility needed to support them appropriately.

Using generalised language to describe individual experiences is damaging. It disregards the need for equity—the idea that each person requires different support to access the same opportunities.

Recognising that every child is unique allows us to adjust accordingly and provide for their specific needs. This is why psychoeducation, disability awareness, and disability consciousness are so important. Disabled individuals must be included in conversations about care and social policy.

As parents, our role is to attune to our children's needs and advocate for them, rather than projecting our own beliefs onto their experiences.

This is why the I SEE YOU project is invaluable. Spaces like this create room for conversation. Art forms, which often don't rely on verbal communication, allow individuals to express themselves beyond words.

Vocabulary itself can be a barrier for autistic and neurodivergent individuals, so we must ensure society offers inclusive, accessible communication avenues. Engaging the senses while educating parents about the diverse needs and impacts of different conditions is key to fostering understanding and support.

The gift and the grief

Sarah

The rites of passage that may never be yours
Fearful, we linger and wonder the contours of your future
Milestones drift as lost peers stride forth
We dwell in limbo, clinging tightly as you carve your way
Life unfolds behind a gauzy veil
A fortress of fear and worry wrapped around you
We witness your pain as you navigate the world
Your delicacy a threadbare shield of protection
As you make an uncertain dance through uncharted lands

But then...

A beauty in connection transcending words and artifice
Lit apart from the tide of ordinary
The purity of your unfiltered smile
An intensity of joy and love
So much unmeasured yet abundant to give
Unexpected glories unvalued by others yet cherished by us
My teacher and guide
A journey of full circle, a completion unearned
Together embracing the unwritten future
The potential not fulfilled
A promise yet to discover-the gift



Visibility matters

Alex

The twins were born at 31 weeks, spending just under two months in special care before coming home.

Due to prematurity, my daughter had a large brain bleed, resulting in left-sided hemiplegia, a form of cerebral palsy. Though mainly physical, it can come with hidden challenges like fatigue, behavioural issues, epilepsy, and learning difficulties. Fortunately, hers is relatively mild and only appears to affect her physically. Unrelated to the bleed, she was also born with a cleft palate (repaired at one) and has mild to moderate hearing loss in her left ear.

My son seemed unaffected by his early birth, but by age 10, we suspected ADHD or autism. High school transition confirmed our concerns—he became increasingly anxious and struggled with sensory overload. We are on the CAHMS waiting list, hoping for an appointment after a two-year wait.

Visibility of disabled people is vital. Two days after birth, we learned about my daughter's brain bleed. My first thought was she would die—my only experience of strokes. The consultant reassured us she wouldn't but would likely have cerebral palsy. Only time would tell.

Strangely, I felt okay. I worked in arts funding with diverse artists and had met many people with disabilities, including cerebral palsy. I'd seen them lead successful, fulfilling lives—it wasn't something to fear.

Hospital appointments were emotionally draining. While most practitioners were supportive, it's hard focusing on what my child couldn't do. I judged myself, never feeling I was doing enough—more exercises, more stimulation. If I could do it again, I'd stress less about milestones. Things happen in their own time. My daughter always finds a way, even if it's different.

Now, the challenge is helping her accept her disabilities. She started high school, made friends, and, like any teenager, doesn't want to stand out. She's never discussed her hemiplegia with friends, nor have they asked. She wears a foot splint and has a weaker hand, so they must have noticed. **This is why visibility matters—so disability is seen as “normal.”**

We're now on a new journey with our son, navigating long NHS wait times and professional dismissal. His school behaviour is exemplary, so he's not seen as neurodiverse. A therapist dismissed ADHD within five minutes. A teacher called him thoughtless. Yet, he is kind and empathetic. No one considered that his behaviour could stem from neurodiversity. It's exhausting to push when professionals insist nothing is wrong, but parents know their child best.

Meeting other parents of disabled children has been invaluable—whether in playgroups, disability groups, or online. It reminds you you're not alone.

Attitudes to disability have improved since my childhood, but there's still a long way to go. Disabled people are some of the strongest and most creative people I've met. I never imagined having two disabled children, but I am proud that I do.