Broken

The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required

> *"The system is broken and no one takes any responsibility. The impact of this on carers, and the constant fight, cannot be underestimated."*
>
> *Family carer*

A Family Carer Perspective

December 2020

Challenging
BEHAVIOUR
foundation

making a difference
to the lives of people with
severe learning disabilities

Contents

Acknowledgments

Thank you to the 214 families whose responses to the survey enabled this report to be produced. The experiences that you have shared are invaluable. To everyone who has been involved in the development of this report, thank you for your time, effort and expertise.

This report was co-written by:

- CBF staff
- Three family carer advisory group members (who chose to remain anonymous)
- Dr Peter Baker (Tizard Centre)

Introduction and Background

Following the Winterbourne View and Whorlton Hall scandals, the general public has become more aware of the trauma that people with learning disabilities and/or autism can undergo. However, what is not widely publicised or understood is the trauma experienced by the individual and their family in their daily lives, caused by interaction with the systems of education, health and social care. These systems are meant to support families to care for their loved one with a learning disability, yet we know that this is not always the case.

> *"Often, community-based services have not been sufficiently well-developed and well-organised to serve them. Placements break down as people whose behaviour presents a challenge can no longer be supported. For those who have been living with their families, there are insufficient local placements prepared to take them. For people already in supported accommodation or residential care, the placement is unable to cope. For some individuals, this means they are required to move from one place to another over and over again, causing distress to them and their families."*
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> Mansell 2: *Services for people with learning disability and challenging behaviour or mental health needs* (2007)

NHS England commissioned a project to help scope the availability of trauma support for family carers of children and adults with learning disabilities and/or autism; what families want, and professional knowledge and awareness. The Challenging Behaviour Foundation, Respond, Three Cs, and the Tizard Centre came together to work on a joint approach to the three strands of work:

The first strand considers what is available to families and what they need. This was carried out by the Challenging Behaviour Foundation and the Tizard Centre through a family carer survey and literature review.

The second strand delivered sessions of trauma support to families and was conducted by Respond.

The third strand looked at professionals' experience of family carer trauma support and was conducted by Respond supported by the Tizard centre via interviews with professionals.

All three strands will be brought together in a final overarching report.

About the Challenging Behaviour Foundation (CBF)

The CBF is the only UK charity focussed on the needs of children, young people and adults with a severe learning disability whose behaviour challenges and their families. There are three interconnected areas of CBF work:

1. **Information and support:** Developing and sharing a range of accessible, practical information and resources to equip and empower families and professionals, to promote early intervention and prevention, support families whose relatives are at risk, and provide casework to families in complex situations.

2. **Campaigning and influencing:** Informed by family support work, this strategic work focuses on ensuring that children and adults with a severe learning disability and behaviour described as challenging and their families are included, engaged and represented in policy and practice at a national, local and individual level.

3. **Promoting best practice**: There is a range of evidence and practice that demonstrates how children, young people and adults with a severe learning disability and behaviour described as challenging can be supported to have a good quality of life within their local community. The CBF is committed to actively sharing and promoting evidence based best practice, including working with researchers and practitioners.

The CBF role in this project was mainly focussed on providing family carer input and experiences to the whole project, including the evidence base for need for trauma based support for families and what they would find helpful.

Focus of this report

This report for Strand One of the project has been co-produced with a family carer advisory group. The CBF recruited the family carer advisory group to co-produce an online survey to:

- Provide the evidence base of need for trauma-based support for families
- Scope out what's available and what works, including evidence-based approaches

This report presents the results of the online survey including family carer comments.

Introduction from the Family Carer Advisory Group

"*We are families who have been traumatised by the continual fights with the very services who are supposed to help us make life easier for our disabled family members. Over the years, we keep coming across other families with disabled children who have suffered in the same way as we have and realised that we were not unique in having to constantly fight the system for even the most basic help for* *looking after our disabled relative. It begins from the point when hopes and dreams of a life bringing up a child are shattered, often by a professional handing out a diagnosis, and continues forever. We, and our children are transformed instantly from being human beings into something lower, because of the way we are treated by the state, by professionals and by the general public. Our main problem is not our relative, but the response from others, especially those who have the power to help but seem unwilling to do so. We feel that change is long overdue, that the present system cannot continue to hurt the most vulnerable in our society, because it is inhumane. Something needs and must be done. We hope that this document will provide evidence that the problem is widespread and that there* ***is*** *a way forward. We hope that people in the various care professions take the time to listen and, most importantly, to* ***act*** *to bring about major change. Perhaps then, we can lead ordinary lives, like everyone else, instead of ones full of trauma."*

Methodology

Three families were recruited to a family carer advisory group to provide their expertise and to co-produce the survey. In discussions with the family advisory group, it was clear that the issue was *complex trauma* and an agreed definition was needed for the project. The group considered existing definitions and, with the other project partners, co-produced the following definition:

> *"Trauma is how a person feels when he/she or someone they love is in a situation that could, or does, cause physical or emotional harm. As a result, the person feels helpless or overwhelmed and the world no longer feels like a safe place. They may find it harder to trust people, feel almost permanently on edge or anxious. It may be more difficult for them to concentrate or sleep, and they may have less patience on a daily basis."*

The family advisory group and the CBF jointly identified key areas to explore in the survey:

- The types of trauma family carers experience
- Whether trauma occurred once or multiple times
- The (ongoing) impact of the trauma
- How traumatic incidents were addressed/investigated
- Whether support was offered or available
- If families found support useful and what they would find helpful
- If families sought their own support and the impact of seeking this
- Identifiable factors which increase the risk of trauma for family carers

The survey was given ethical approval by the Tizard Ethics Committee which will allow the findings to be disseminated via publication in a peer reviewed academic journal. The CBF also acknowledged that, due to the subject nature of the survey, it may have been difficult for some family carers to complete. At the beginning of the survey the availability of the CBF's family support line for family carers of individuals with severe learning disabilities whose behaviour challenges was highlighted. For families supporting relatives with moderate-mild learning disabilities, the CBF signposted to other organisations who offer appropriate support.

Due to the complexity of the issues, a detailed survey was necessary to gain a comprehensive picture of family experiences. It was estimated that the survey took 30 minutes to complete.

Survey circulation and profile of family carers

The survey was published on Survey Monkey and disseminated by the CBF to its networks of family carers and professionals and on its social media platforms. People were encouraged to share the survey widely with their networks to increase the reach. The survey was designed specifically for **the family carers of a child[ren]/adult[s] with a learning disability and/or autism in England**. However, 2% of respondents were from Scotland and 3% from Wales. Participation was voluntary and no personal details were collected, nor any contact made unless survey respondents consented to this or there were safeguarding concerns.

The survey was available for a three-week period (25th February 2020-16th March 2020) and received 214 responses, despite the survey's difficult subject matter and long length. The majority (87%) of participants were mothers, the next largest category of participants was siblings at 7%. More information on family carer profiles can be found in Appendix A, Table 1.

The majority (61%) of the children/adults with a disability and or/autism were living at home and 38% were living in a range of various types of care provision, including 5% in an Assessment and Treatment Unit. The majority of family carers had experience of caring for a loved one with disability and support needs. 91% indicated that their loved one had a diagnosed or suspected learning disability and/or autism; additional diagnosis of developmental delay; additional needs; or special educational needs.

Types of traumatic events and their impact

The survey asked families to identify whether their loved one had experienced various types of trauma specific to learning disabilities and/or autism, as well as any mainstream trauma and whether these traumatic incidents happened once or multiple times.

> *"* [Trauma happened in] *Many settings, residential schools [they were] abused by staff and residents. Also was placed in a secure unit with convicted child murderers and subsequently badly beaten by one. A head teacher smashed out my son's front teeth."*

> *"My daughter was handcuffed by the police and put face down on the floor in* [her] *own home. Then being taken away in an ambulance without anyone to act as [an] interpreter or advocate. Having a blood sample taken from them whilst in ambulance whilst in handcuffs behind her back. At hospital when I*

> *arrived to find her, I was denied access until I demanded to see the papers which specified that I could not see her. The care home that she was taken to didn't want us to see her for three weeks, and when we were allowed to see her she had multiple bruises and was so drugged that she didn't recognise me for about half an hour."*

> *"Put outside due to his challenging behaviour even in winter months. Left to play in dirty drains in the summer months with only part of his clothing on (parent witnessed this). I complained to the head but nothing was done. Left in teaching cubicle on his own made to complete his tasks by himself due to insufficient staff, unable to get out, parent witnessed this. Many complaints were made to social workers and local authority but everything was covered up or ignored. This was a Special school with a fairly new teach unit for autism. This school eventually failed and was shut down. A relief for future children."*

> *"Extreme difficulty getting our local authority to help our son or ourselves in any way. Huge personal & financial burden as a result of the above, including a legal battle to get our son the help he had been entitled to, but not received, for many years. The inability to experience any kind of 'normal' family life, leading to feelings of isolation and hopelessness/helplessness."*

The most common types of trauma/situations which individuals with learning disabilities and/or autism and their families experienced multiple times were:

- Loss of familiar routines, environment, people (59%)
- Subject to 'rules' which may not be understood (e.g. not allowed access to preferred items/activities) (46%)
- Not getting care support needs met easily in a timely manner (50%)
- Not getting health needs met easily in a timely manner (41%)

Other types of trauma families identified can be found in Appendix A, Table 3.

Families identified different types of traumatic incidents experienced, and often families had undergone more than one type of incident. We know that mainstream traumatic incidents (e.g. life-threatening illness, poverty) also happen to people who are family carers. Families indicated in the questionnaire that 14% had experienced a single incident of mainstream trauma, 30% had experienced multiple incidents and for 29% the impact of this was ongoing.

The trauma families experience as family carers of a child or adult with a learning disability and/or autism is *in addition* to mainstream trauma.

The survey results showed that **trauma for family carers is multi-layered and has a significant impact on them emotionally.**

> “*[Trauma happened] In 2 schools from aged 4 to 9. Since then not in school. Includes being dragged out of my car into school and dragged into school off the street. ADHD meds given to enforce compliance in school. Multiple incidents [of trauma] during legally enforced contact with abusive parent. These include being locked in a small room, being dropped and being thrown. This also ended aged 9 when child had a suicidal breakdown. I was forced to prepare for and attend several traumatic family court appointments over this period. During some I was treated like a criminal and spoken to and about in the most scornful manner. I had been accused of FII* [fabricated or induced illness], *abuse, dishonesty whilst continually fighting for the well-being of my child. I was harassed by a head teacher until I stated that I would be seeking legal advice on the matter. The head teacher had informed my GP and other medical and educational professionals of her opinion that I was an abuser. Eldest child’s PTSD symptoms are ongoing. Their multiple diagnoses indicate susceptibility to mental health illnesses (severe). My PTSD symptoms also ongoing although as controlled as humanly possible. The worst period from when child aged 8 to 9, I had lost my mother traumatically with dementia in awful care situations, younger child also displaying autistic traits that were attributed to my supposed abuse. I had been vulnerable and in situations of domestic abuse for various periods before children and also continuing whilst they were small in insidious ways. I had breast cancer and multiple ops including full mastectomy and ostectomy, sending me into sudden menopause during this period. 2 years of mental hell whilst fighting for the human rights of both children. Both suffered MH issues. Now both home educated. I developed severe chronic pain and fatigue. The fatigue persists with lesser pain. In addition to this, I was assessed as being on the autistic spectrum myself last year (formal conclusion and report not arrived despite my chasing it several times). I can supply place and assessing Doctor to prove this is true. I have been proven right about all my intuitions regarding my children’s diagnoses and needs. I meet those needs myself with very little help. The years of struggle and mental anguish have come at a cost. This coming Tuesday I’m back in for tests and scans regarding recurrence of breast lump. I am terrified of what may be for my children - most particularly my eldest - if I die over the next coming few years. This is in a nutshell.”*

Families were asked to identify whether they had experienced any of the following as a result of the traumatic incident/s:

- Panic attacks
- Insomnia/disturbed sleep pattern
- Unable to work/job loss
- Disagreement with friends/family members
- Family members leaving home
- Relationship breakdown
- Depression
- Anxiety and fearfulness

- Personality change (i.e. difficulty trusting others)
- Guilt

59% of families said they experienced guilt regularly, and **over 72% of participants had experienced all of the above at least once.** More information can be seen in Appendix A, table 4.

> *“Unable to function - panic when the phone rings. panic when the doorbell rings. Can't focus. Can't trust anyone ever. Find it extremely difficult to keep calm with 'professionals' who are utterly ignorant of Autism, (and most of them are). I overthink everything, relive it every day.”*

What causes trauma?

The survey shows that much of the trauma experienced by family carers seems to be as a result of systems which are meant to be in place to support them. Education, Health and Social Care systems, as well as members of professional bodies within them, are responsible for meeting the needs of individuals with a learning disability and/or autism. The failure to do this is traumatising families.

> *“An overwhelming sense of powerlessness. At any moment I can lose everything and everyone I love, no matter how hard I work or try. Impotent rage at a system that works against common sense and basic support needs. Feel like a beggar. At worst times felt like systems wanted us dead as it would be cheaper. Considered driving me and my son off a cliff because of how strong this feeling was over 2 years with no way out”*

> *“Exhaustion and a sense of complete isolation and hopelessness at the constant fight to get child’s needs met while no one listens and often hints at parent blame or exaggeration. Loss of friends, social life, a breathing space (child mostly out of school as schools couldn’t meet needs) plus at the same time trying to understand a very opaque system and do hundreds of hours of paperwork without guidance. Trauma from seeing your child in extreme distress and not always being able to help or get them help as CAMHS knock back referrals”*

> *“Put simply, families simply focus on the impact that service failures have on their loved one with a Learning Disability and Autism (in our case) and keep fighting to reduce the chances of repeating such experiences. The impact of repeated exposure to abuse or service failures leave a fatigue and acceptance that poor responses are the norm. There’s never any time to think about how this impacts on themselves.”*

> *“Many many times over the years we have had services fail to meet the basic needs of my brother. Education services caused huge trauma by locking him in a room and lying to my parents about this. He always came home from Respite services withdrawn and with physical injuries. This caused long periods of crying and distress. My brother was unable to verbally communicate his emotions and self injury began in teenage years. These services again persistently lied about his experiences with them. Day centre*

> *services as an adult persistently discriminated against him and denied access to numerous activities & services. Supported living provider abused him physically & financially, emotionally & psychologically. Trauma was unprecedented. GP & Acute hospital ignored his physical health status & symptoms. They turned him away with prescribed & unnecessary antibiotics. He collapsed and died at home as a result of pulmonary embolism just 2 hours after what was his 3rd presentation via emergency services."*

Loss/disruption of familiar routines can be an unwanted side effect of many of the 'solutions' education, health and social care offer as part of the system to support families, such as placements out of area or large residential settings. This loss/disruption could, in and of itself, be traumatising or remove available coping resources.

When families were asked to identify the **risk factors** that they thought increased the likelihood of trauma, they identified:

- Lack of services and support to meet my relative's individual needs (81%)
- Lack of early intervention services and support (77%)
- Lack of specialist support i.e. trained staff/support workers with learning disability experience (76%)
- Finding a way through the education, health and social care system (71%)

54% of families felt all the factors listed increased the risk of trauma. More risk factors can be seen in Appendix A, Table 14.

Family carers of children and adults with a learning disability and/or autism can clearly identify exactly what in the system is causing and is likely to cause them trauma. If families are able to do this, then it should be possible for commissioners, local authorities, clinicians and other professionals to do the same.

Evidence of the system traumatising families is also clear from the number of potential safeguarding concerns that the CBF identified from the results of the survey. 146 responses were identified as having a potential safeguarding concern that needed following up. The CBF was unable to follow up with 68 of these concerns as no contact details were provided.

In the main, concerns were regarding the safety of an individual in their current care provision. Of note was that no safeguarding concerns were raised concerning the capability of any of the parents/family members.

Results from the survey also suggest that the system was poor at acknowledging the trauma caused, suggesting that it is not currently identifying risk factors in the same way as families. 22% of families did not have their trauma acknowledged by any professional agency.

> *"All the services involved failed my child, investigations failed to hold anyone to account. In the case of the special school, at least my child is no longer there due to success at Tribunal (at great personal and financial cost). I rarely put my trust in any professional now and follow the evidence, questioning every detail until I can ensure my child is adequately safeguarded."*

> *"I used to think that this country was better than many others because I thought that on the whole people were treated fairly. But I don't feel that anymore. There is no body that is independent and has the power to defend disabled vulnerable people stuck in care homes ATUs and psychiatric hospitals. Safeguarding is a part of the local authority, so is the DOLS department and even advocacy such as XXX is paid by the local authority. The CQC passes on information to safeguarding. It is too dangerous to make a complaint about a care home because it's impossible to be anonymous and so no-one risks the care home staff taking it out on the vulnerable person in their care. Social services hound parents and lie about them in court so the whole experience of having a disabled relative is scary and makes one traumatised all the time. I am so worn out by all of this and fed up that I can't protect my daughter adequately."*

Support family carers currently have access to

Despite the role the system plays in traumatising families, there is currently relatively little in the way of support offered to them by that same system.

> *"We were not supported - we were expected to carry on despite my child suffering so much trauma. I personally feel they forgot we were human and had feelings and that we had no right to expect humane treatment."*

> *"Requests for support vigorously rejected by local authority."*

> *"I am aware that there appears to be no such support whatsoever in my area."*

Families were asked to identify (from a list of several types of therapy and counselling) what they had been offered, and whether they were able to access this.

> *"If you think any of the above "support" exists you are in cuckoo land. Or do you class support as providing a leaflet or website?"*

Over 50% of people were not offered any of the options listed. Less than 7% indicated 'support had been offered but not accessed' for each support type. When asked why the support was not accessed families indicated (37.5%) that the support type offered had been 'inappropriate'.

> *"Most was not offered those that were we couldn't travel the distance"*

> *"Went to Henley from London because I was desperate."*

This would suggest that the support being provided is not tailored to meet the specific needs and circumstances of children and adults with learning disabilities and/or autism and their families. This is supported by the number of people who left comments on this section (47.5%). Examples include one participant reporting his son was too traumatised to speak to a stranger; another highlighting the absence of a mediator at the CPA and further comments regarding the lack of availability for home-based support.

Not only were families offered relatively little support, when it was offered, suitable adjustments were not made in order for families to be able to access it.

> *"Nothing whatsoever has been offered. I was referred to Adult Mental health - they rejected the referral despite me being suicidal. My GP just said 'you won't do it'. They said they would refer me back to primary services, but then months later, they had not done it. I asked the GP to help, she said 'there's not much I can do about it as you're too aggressive.' I am not 'aggressive' - I am desperate and suicidal and have NO HELP. I asked for Trauma therapy, no one did anything. I am currently having to pay for counselling, it isn't really helping much because I can only afford it once a month and it's not Trauma therapy."*

> *"6 weeks face to face CBT offered by CAMHS but inaccessible due to not being adapted to meet the needs of a child with selective mutism/possible Autism and distrust of professionals after traumatic experiences with professionals in high school."*

Families seeking their own support

Families were asked to indicate whether they had had to seek their own support and were given the same options of support types as in previous questions. Families were able to independently locate a wider range of support types than they were actually offered. This could suggest that there is support provision available, but that it is not being offered, or that the only support available is privately sourced and paid for. This is supported by the number of people who were aware of the existence of the different support types. Over 70% of people were aware of the different support types.

> *"Only understand the condition ASD, ADHD. I had to pay for counselling myself and seek support of my child's possible PDA condition. I took CBT, but it wasn't linked to my role as a carer."*

> *"There was very little, if at all any support offered but I pro-actively sought support for my son and family. We accessed Attachment Therapy."*

> *"The only support that was offered to me was because I have asked and researched it myself. Nobody really cares if you don't ask when desperate. Sadly."*

> *"The only support we've been able to get for our child has been things we have researched, found and funded ourselves as far as budget would allow e.g. sensory OT, play therapy and psychiatric support when suicidal"*

The issue is not a lack of family carer awareness of support. Families either already know this support exists, or have discovered through their own research that it is something which should be possible. However, comparing these responses with the number of people who are offered and receive support suggests that support which should exist is simply not being offered to families.

Impact of seeking own support

Engaging in a search for your own support, while already traumatised and dealing with ongoing care and support needs for a loved one, had a considerable negative impact on families who responded to the survey:

- 62.96% of people experienced an emotional impact
- 45.93% experienced a physical impact
- 45.93% incurred a financial cost
- 56.3% felt that a great amount of time was needed to seek the support (an additional burden when you are a traumatised family carer)
- 38.52% experienced social isolation
- 41.48% experienced tension with/isolation from family
- 19.26% experienced all of the above.

Not only are families overwhelmingly traumatised by the system, as shown by the unmet care and support needs identified in the survey, the lack of appropriate support within the system to address this is compounding the trauma suffered by these families.

> *"Causing my physical health condition to become worse due to the amount of time and energy used trying to seek support for my child."*

> *"It is one of the many additional things you have to do."*

> *"Fighting for help made me feel worthless. Society doesn't care."*

> *"It has been very very challenging over the years. It has affected my health physically and mentally had to give jobs up, put on weight and financially has been very worrying."*

Plugging the gap

In addition to families searching for their own support, the survey suggests charities are also 'plugging' the gap in support. In the survey responses, the support type with the highest incidence of both being offered *and* independently located was ‘charitable organisations’.

There was a high satisfaction rate with specialist face-to-face counselling both where this was offered or independently sought. However, this was only offered to 7% of participants, and 44% were not able to locate it themselves. This indicates a need for more specialist counselling for families.

> *“I feel that paid professionals only seem to be brought in when a crisis has already happened. This is usually too far down the line. We as a family highlighted our relative’s declining situation 18 months before they got sent miles away in a knee jerk reaction as it was 2 weeks before Christmas and was the only bed available. This unfortunately was where our family member was horrendously attacked. I’m angry and guilt ridden all the time that these so-called professionals allowed this to happen because the correct checks had not been done. Our loved one and our families have all been negatively and heartbreakingly affected by this situation and it’s still ongoing. More protection is needed for vulnerable people and their families.”*

Families also indicated in the comments that the most helpful support they received was from charitable organisations.

> *“Charity organisations have been a god send. Had to seek them out ourselves or offered [through] other charity groups”*
>
> *“Charity - Unique Rare Chromosome offers an open platform for parents to discuss issues.”*
>
> *“CBF were helpful in sorting out some things, but the problem hasn't been solved. My daughter is still living in the care home and she's not being adequately looked after and she's still signing to come home and stay at home.”*
>
> *“Local branch of national autistic society peer support very supportive. Also victim support one particular lady hugely supportive that was in telephone for a year every week”*
>
> *“CAMHS were relieved when I told them I had called the Samaritans out of desperation in 2015. They said it was a great idea and would tell other parents to do this. Pity that services are so restricted that I was forced to ring a suicide line for my 9 year old.”*
>
> *“The advice and support I received from the voluntary sector was invaluable- and importantly it was wonderful to be able to talk to others with similar experiences. “*
>
> *“Felt hugely supported by the CBF and local organisation Oxfordshire Family Support Network”*

> *“I have got more from speaking to the CBF than anyone else. Even just knowing there is someone familiar at the end of the phone if needed helped.”*
>
> *“I had great support from 3 charities. CBF. Mencap. And X a non-profit small Advocacy charity In so many ways. Thanks to these 3 wonderful organisations I survived. At one time I almost took my life when my son was badly physically abused. Thanks to X I got her to represent me and my views. Thanks to CBF, letters were written and phone calls were made to me and I was not alone. Thanks to Mencap, I got outside support to fight my child’s rights. And I became a campaigner and not a statistic.”*

In addition, families suggested that peer-support groups would be useful. This finding combined with the reported benefits of charities, would suggest that families are looking for support where the people they interact with can understand/empathise with their experience.

> *“Unique online support group have been amazing I'd it hadn't been for them since my daughter's diagnosis I don't know where I would have been.”*
>
> *“I got a lot of support from my local carer support group.”*
>
> *“Accessed CBF family carer forum by self.”*
>
> *“Autistic support groups and PDA action group have been helpful with information etc.”*

Charities were likely to be identified as useful as they were one of the few support types which was offered or easier to find. The satisfaction of families with charities suggests that not only are they more widely available (unlike other support types), but they are also doing something right to support traumatised family carers and are plugging a gap where other support is not offered or is inappropriate.

Specialist learning disability trauma support should be one of a *range* of options that Health and Social Care develop and make available to those who need it. Other non-specialist suggestions from families included:

- Support groups bringing families together
- Choice from a range of provision/support/services

Charities are not the only form of support plugging the gap, families have indicated that they are relying on one another to do this too.

One family carer told the CBF how her son was traumatised by abuse that he had undergone, and she was also suffering PTSD from this. Due to a lack of support, she had to support her son with his trauma, while retraumatising herself in the process. She also indicated that she offered support to other families as she knew this was not available elsewhere. But many families may not be in a position to provide support to others and nor should they have to.

Therefore, support groups, while a useful way for families with similar experiences to connect, can potentially cause re-traumatisation and place the burden of dealing with trauma on the families again. Though these groups would be useful, they should be offered in conjunction with other types of support. There should be a **range of provision offered to families without constraint**, and peer-support groups should have input from an appropriately trained professional to avoid re-traumatisation.

> *“Face to face counselling offered for six weeks. Felt worse as there shouldn’t have been a time limit. I wish I’d never done it, time constraints caused PTSD symptoms to worsen. I also felt guilty that the person really suffering wasn’t being offered anything at all.”*

> *“The therapy I got was not offered to me by anyone. I had to refer myself for therapy. They give 6 sessions and then leave you whether it's helped or not. None of those therapies worked and I'm still suffering from PTSD and depression.”*

> *“Time-limited support not helpful when problems are long-standing and ongoing. CBT model of therapy, with emphasis on 'fixing the person' when sometimes it's the situation that needs fixed, was experienced as deeply unhelpful – presenting the parent as culpable solved nothing and created new problems ("I must not be trying hard enough if I still feel bad about this - another failure to add to the others. Now I don't just feel bad, I feel worse.")”*

Covid-19

Survey responses show that the system could address risk factors and reduce the trauma and need for trauma support. But there is also a clear need for better and more accessible trauma support *now.*

The fact that a high number of families are actively seeking support when they are not offered it, reveals that there is a clear need for more widely available trauma support for families. This is supported by the high response rate to a relatively long survey which was only available for three weeks. This suggests that there is a gap in support which families are plugging by searching for their own.

After the questionnaire had been completed and the survey analysed, the country was subjected to restrictions due to the Covid-19 pandemic. Covid-19 has highlighted the inequalities in our society, even more. The restrictions imposed create settings where the risk factors identified by families as increasing trauma are more likely to be prevalent.

Immediate support needs to be developed to ensure that those who are traumatised during this period are proactively offered trauma support if needed.

What needs to happen now?

Throughout the survey, family carers expressed mistrust in the system's ability to appropriately support them and their relative generally, but also to specifically support them when they are traumatised.

> *"I felt I was going mad. Couldn't listen to the professionals, felt so angry with everyone."*

Sadly, families have learned to mistrust the system through their interactions with it:

> *"Exhaustion, stress caused when challenging system that ignores despite evidence, and as parent you sound confrontational and hate it."*

The survey responses show that trauma experienced by family carers is a result of a combination of many challenges to overcome that are caused by the system in addition to dealing with the mainstream trauma that we all have to manage in life.

The survey results show that the failures of the system impact the individuals and their families most heavily- not the people responsible for those failures. The Government, NHSE and CQC have all made commitments to the Transformation of Care, yet this survey suggests that its failure to transform continues to have a significant and long-term traumatising impact. All parts of the system must be held to account, acknowledge their negative impact and prioritise action that delivers change for families and their loved ones.

Recommendation 1: The system should not traumatise families in the first place. The system, including commissioners, local authorities, clinicians, support staff, professionals and senior officials must recognise and address the risk factors for trauma that families have identified in this survey.

Achieving this will require:

- Investment in ensuring that there is a joined-up Education, Health and Social Care system to ensure appropriate support is provided and maintained for children and adults with learning disabilities and/or autism and their families to enable them to get the right support, in the right place, at the right time.
- The existing initiatives within the system working robustly everywhere and in a timely manner to deliver good outcomes for individuals e.g. annual health checks
- The Oliver McGowan Learning Disability and Autism mandatory training should include identifying risk factors for trauma in order to mitigate them. This will lead to a trauma-informed approach.
- Professional bodies of the learning disability workforce ensuring that their members are sufficiently trauma-informed and trauma-trained; that they understand and comply with the relevant legal frameworks e.g. Mental

Capacity Act and that all frameworks and pathways include trauma risk and support

Recommendation 2: When trauma does occur, there needs to be a pathway in place to offer individuals and their families a person-centred trauma support package. This should not be at a financial cost to the families. This package should allow individuals and families to access the range of support types that they need whenever they need it and should not increase the burden on families to look for or provide their own trauma support.

Achieving this will involve:

- Every local area acknowledging the need for a trauma pathway
- Every local area co-producing the trauma support pathway with families
- Investment in making specialist support available for all individuals and family carers who need it (see training bullet point under Recommendation 1).
- Learning from the support that charities provide that families value and find helpful
- Working with families to co-design individual packages of support that are flexible and person-centred
- Developing a range of support types such as facilitated support groups, and promoting health and wellbeing activities that are accessible to family carers

Recommendation 3: Develop more widely available specialist trauma support for immediate effect to help those families who are already traumatised.

Achieving this will involve:

- Urgently increasing trauma support capacity via funding and training to ensure that there are counsellors and professionals available for those who have been traumatised.
- Proactively planning to meet the trauma support needs of those who are likely to be traumatised by pandemic restrictions. There will be an immediate support need for families coming out of lockdown.
- Investing in mainstream trauma support services to equip them to better support people with learning disabilities and/ autism and their families
- Ensuring specialist support services are available and accessible in a timely manner to those who need it
- Build on what is developed now to facilitate recommendations 1 and 2

Conclusion

This survey shows that the trauma of family carers of children and adults with a learning disability and/or autism is multi-layered and complex, with many families experiencing a wide range of trauma and receiving little to no support for this. Families also experience an additional burden by needing to independently search for their own support.

Results show overwhelmingly that negotiating a way through the system that is meant to be in place to support families is contributing to the trauma. This trauma could and should be avoided in the first place. The impact of this trauma on families is high and ongoing – 59% experience guilt regularly, with relatively little support in place to help them.

Many family carers actively seek their own support at great emotional and financial cost. When trauma does occur there needs to be a pathway in place with a range of support types available that can cater for individual needs. The number of people who responded to a long survey on a very difficult topic highlights the extent of unmet need. A lack of research evidence suggests that more attention should be given to this area. Nevertheless, this should not delay the provision of support which needs to be developed *now* for those traumatised families who completed the survey, those with safeguarding concerns raised, and those who are likely to come out of lockdown even more traumatised.

The evidence from this survey suggests the need for a both a short-term approach to provide immediate support, and a long-term approach to stop the source of trauma and develop individualised pathways.

Final Word

“Nothing will change because no one cares about disabled children, nor the families that care for them. This is evident in the shambolic education EHCP plans when disabled children cannot even get their legal entitlement to education without repeated costly legal battles. In previous years, children used to live in institutions because the enormous toll on the entire family of raising said disabled child was understood. I think we have gone too much the other way, and now this massive strain is borne too much by vulnerable families at massive cost to all involved. We need a happy medium for all, and for the most challenging children and their families the solution is not some counselling and a bit of support to keep them buffing along in a horrendous situation like emotional slavery. It is choice.”

“The content of the questions [in the survey] *are very wide and are almost the first step in recognising that this area is a massive issue”.*

“Far too much power lies in the hands of inefficient social workers and commissioners who know nothing about the diagnosed conditions they feel empowered to dictate about. They are paid to care for those in their care and yet they do the very opposite and cause havoc, grief and trauma. Why are there never investigations into what social workers do by our society and government? How can

they spend the public purse with such horrendous outcomes of trauma for all the family? Why does our society do this to the vulnerable and innocent who don't deserve punishment of the type they deal out to us?"

"Horrendous system has broken so many families. [it would be better] *If the system would admit its short comings and lack of funding rather than gaslight and blame parents for seeking support or for having a disabled child."*

We want this work and this report, which has highlighted the issues, to lead to action so that "the system" is not traumatising but supportive. This report, based on family carer experiences, makes grim reading. But it shines a light on an often-hidden issue and provides evidence of the need for change.

Working together we can drive this change – to really make a difference and deliver the positive outcomes we all want to see.

A full report of all three strands of this project is available here (link to be added when available).

Appendix A:

Family Relation	Responses	
Mother	87%	186
Father	3%	7
Sibling	7%	15
Grandparent	1%	1
Aunt	1%	4
Uncle	1%	1
Cousin	1%	1
Other	4%	9

Table 1 Family Relationship to person with a learning disability and/or autism

Focal persons residence	Responses
At home with their family	61% (131)
In a care home	11% (24)
In a residential school	2% (5)
In a supported living arrangement (individual)	14% (31)
In a supported living arrangement (shared)	5% (10)
In a hospital/Assessment and Treatment Unit (ATU)	5% (10)
With a relative other than a parent	1% (2)

Table 2 Place of residence of person with a learning disability and/or autism

Type of event	Single incident	Multiple incidents	Multiple incidents not known but suspected	Impact of traumatic experiences is ongoing
1. Mainstream Trauma: e.g. life-threatening illness	14% (31)	30% (65)	3% (6)	28% (59)
2. Separation from family and restricted visiting	7% (14)	32% (69)	3% 6	29% (61)
3. Loss of familiar routines, environment, people	7% (15)	51% (109)	2% (5)	34% (72)
4. Out of area placement	11% (23)	21% (45)	2% (5)	21% (44)
5. Sharing living space with unfamiliar people- who may be in crisis e.g. in an ATU, respite/short breaks service, school or other educational setting	6% (12)	33% (70)	4% (8)	22% (47)
6. Subject to "rules" which may not be understood (e.g. not allowed access to preferred items/activities)	4% (9)	46% (98)	7% (14)	26% (56)
7. Physical Restraint	10% (21)	37% (80)	6% (13)	25% (54)
8. Mechanical Restraint- i.e. being strapped in a chair/wheelchair	5% (10)	6% (12)	4% (8)	7% (16)
9. Chemical Restraint i.e. PRN/antipsychotics/psychotropics	5% (11)	25% (54)	3% (6)	18% (38)
10. Seclusion- being separated from any other people and prevented from leaving either by a lock or supervision	3% (7)	31% (66)	5% (10)	20% (42)
11. Physical abuse	6% (13)	23% (49)	9% (19)	15% (32)
12. Sexual abuse	6% (13)	3% (6)	4% (8)	6% (13)
13. Psychological abuse	10.81% (12)	28% (59)	16% (34)	19% (40)
14. Not getting care support needs met easily in a timely manner	4% (8)	50% (106)	10% (21)	32% (68)
15. Not getting health needs met easily in a timely manner	4% (9)	41% (87)	8% (17)	28% (60)
16. Other	5% (11)	11% (24)	2% (4)	13% (28)

Table 3 Percentage (and number) of participants who had experienced adverse life events

Response	Regularly	Sometimes	Intermittently	Once	At least once
Panic attacks	20% (43)	21% (45)	14% (31)	3% (7)	79% (169)
Insomnia/disturbed sleep pattern	62% (132)	14% (29)	9% (20)	1% (2)	90% (192)
Unable to work/job loss	32% (68)	15% (32)	11% (24)	5% (10)	78% (166)
Disagreement with friends/family members	31% (66)	29% (62)	13% (27)	1% (3)	84% (179)
Family members leaving home	10% (22)	6% (12)	3% (7)	7% (16)	73% (156)
Relationship breakdown	15% (33)	11% (23)	11% (23)	9% (20)	78% (166)
Depression	41% (87)	19% (40)	15% (33)	1% (2)	85% (182)
Anxiety and fearfulness	62% (132)	14% (30)	10% (22)	1% (2)	89% (190)
Personality change (i.e. difficulty trusting others)	38% (81)	20% (43)	10% (22)	1% (3)	82% (175)
Guilt	59% (126)	16% (34)	7% (16)	1% (1)	87% (187)

Table 4 Percentage (and number) of participants who had experienced responses to impactful events

Agency	Responses
Care Quality Commission	12% (25)
Service Provider	23% (50)
Health and Social Care Ombudsman	5% (11)
Commissioner	9% (20)
Local Authority (Council)	29% (61)
Local Authority Safeguarding department	29% (62)
Doctor/psychiatrist	25% (54)
School (teacher, assistant, administrator, head, Special Educational Needs Coordinator)	21% (46)
Police	21% (45)
All of the above	1% (2)
None of the above	22% (48)
Other (please specify or provide details):	24% (51)

Table 5 Acknowledgement of events by agencies

Type of support	Support offered	Support not offered	Support received	Another family member received support	Focal person with a disability received the support	More than one family member received the support	Support offered but not accessed
1. Specialist counselling (face to face)	7% (14)	51% (109)	11% (23)	5% (10)	7% (14)	6% (12)	5% (11)
2. Generic counselling (face to face)	8% (17)	51% (110)	12% (26)	5% (10)	3% (6)	3% (6)	6% (12)
3. Specialist counselling (via telephone/video call)	1% (3)	64% (138)	6 (3%)	1% (1)	1% (1)	1% (2)	1% (3)
4. Generic counselling (via telephone/video call)	1% (1)	64% (138)	1% (3)	1% (1)	1% (1)	0% (0)	2% (4)
5. Group therapy	3% (6)	58% (125)	5% (11)	1% (1)	1% (3)	3% (6)	2% (5)
6. Cognitive Behavioural Therapy (CBT)	6% (13)	55% (117)	6% (12)	2% (4)	4% (9)	1% (3)	3% (6)
7. Charitable organisation e.g. Challenging Behaviour Foundation or Samaritans	10% (9)	50% (108)	11% (23)	2% (4)	2% (5)	1% (3)	1% (3)
8. Other	10% (21)	24% (51)	6% (12)	1% (2)	3% (7)	1% (3)	1% (2)

Table 6 Support offered and received

Reason for not accessing	Percentage of respondents to this item
Inappropriate support type offered	37.5% (15)
Time commitment not possible	22.5% (9)
Waiting list too long	12.5% (5)
Fees	10% (4)
Support too far away/not accessible	7.5% (3)
Sessions offered were not at appropriate times	7.5% (3)
All of the above	5% (2)
Other	47.5% (19)

Table 7 Reasons for not accessing offered support

Satisfaction with	**No of responses**	**Weighted average**
1. Specialist counselling (face to face)	53	4.8
2. Generic Counselling (face to face)	44	4.2
3. Specialist counselling (via telephone or video call)	14	4
4. Generic counselling (via telephone or video call)	12	4
5. Group Therapy	19	3.6
6. Cognitive Behavioural Therapy (CBT)	32	3.75
7. Charitable organisation	36	5.1

Table 8 Offered support satisfaction ratings

Type of support	Able to locate	Unable to locate	Personally received	Another family member received	Focal person received	Multiple family members received	On waiting list
1. Specialist counselling (face to face)	39.71%	44.12%	11.76%	8.82%	8.82%	0.00%	8.82%
2. Generic counselling (face to face)	45.10%	29.41%	9.80%	11.76%	7.84%	1.96%	9.80%
3. Specialist counselling (via telephone/video call)	34.62%	42.31%	3.85%	0.00%	3.85%	7.69%	7.69%
4. Generic counselling (via telephone/video call)	37.50%	43.75%	0.00%	0.00%	6.25%	0.00%	12.50%
5. Group therapy	38.10%	33.33%	19.05%	4.76%	4.76%	0.00%	4.76%
6. Cognitive Behavioural Therapy (CBT)	43.75%	31.25%	15.63%	6.25%	12.50%	0.00%	0.00%
7. Charitable organisation	70.83%	12.50%	8.33%	2.08%	6.25%	4.17%	2.08%
8. Other	48.15%	22.22%	18.52%	3.70%	7.41%	0.00%	3.70%

Table 9 Support independently sought

Satisfaction with:	**No of responses**	**Weighted average**
1. Specialist counselling (face to face)	42	4.6
2. Generic Counselling (face to face)	38	4.4
3. Specialist counselling (via telephone or video call)	13	4.6
4. Generic counselling (via telephone or video call)	10	4.1
5. Group Therapy	14	4.2
6. Cognitive Behavioural Therapy (CBT)	21	4.0
7. Charitable organisation	38	4.9

Table 10 Independently sought support satisfaction

Impact of independently sourced support	Percentage of respondents
Emotional impact (depression, anxiety, panic attacks)	62.96%
Physical impact (weight loss, weight gain, adverse effect on health)	45.93%
Financial impact	45.93%
Great amount of time needed to seek support	56.30%
Social isolation	38.52%
Tension with/isolation from family	41.48%
All of the above	19.26%
No impact	8.15%
Other	5.19%

Table 11 Need for/impact of independently sources support

Support	**Currently aware**	**Aware prior to traumatic event**
1. Specialist counselling (face-to face)	15% (32)	6% (12)
2. Generic counselling (face to face)	20% (42)	7% (16)
3. Specialist counselling (via telephone or video call)	14% (30)	4% (8)
4. Generic Counselling (via telephone or video call)	12% (25)	5% (11)
5. Cognitive Behavioural Therapy (CBT)	22% (47)	8% (18)
6. Group therapy	11% (24)	5% (10)
7. Charitable organisation	28% (60)	9% (19)
8. Other	5% (11)	1% (2)

Table 12 Awareness of available support

Support	Percentage of participants
1. Specialist counselling (face-to face)	65% (139)
2. Generic counselling (face to face)	16% (34)
3. Specialist counselling (via telephone or video call)	35% (75)
4. Generic Counselling (via telephone or video call)	9% (20)
5. Cognitive Behavioural Therapy (CBT)	26% (55)
6. Group therapy	31% (67)
7. Charitable organisation	27% (58)
8. Other	26% (56)

Table 13 Potentially helpful support

Perceived risk factor for family trauma	Responses
Lack of services and support to meet my relative's individual needs	81% (173)
Lack of early intervention services and support	77% (165)
Lack of specialist support i.e. trained staff/support workers with learning disability experience	76% (163)
Finding a way through the education, health and social care system	71% (153)
Trying to access the right support	69% (148)
Lack of a joined-up education, health and social care system	68% (146)
Families acting as only form of emotional support for relative	64% (136)
Loss of familiar routines, environment, people	60% (129)
Subject to rules which may not be understood (e.g. not allowed access to preferred items/activities)	60% (128)
Inappropriate physical environment	54% (115)
All of the factor listed here	54% (115)
Restrictive Interventions	53% (113)
Seclusion	52% (112)
Neglect	52% (112)
Sharing living space with unfamiliar people – who may be in crisis	51% (109)
Potential over-use of anti-psychotic and psychotropic medication	50% (108)
Out of area placement	50% (107)
Separation from family & restricted visiting	49% (104)

Table 14 Perceived risk factors for family trauma