PARENT CARER TRAUMA

A discussion paper on trauma and parents of children with Special Educational Needs and Disabilities (Parent Carers)

For professionals and parent carers

May 2024

> *‘Trauma-informed services recognize the need for the whole family to be given time and attention. It is crucial that parents receive the support that they want and need when they are ready (not what and when suits the system) to reduce feelings of helplessness.’*
> *(Emerson, 2019, p. 13)*

Parent Carer Trauma Working Group

This is a working document capturing key points discussed at the Parent Carer* Trauma Working Group during 2022-24. The working group was established by a network of people who believed that parent carer trauma was often unrecognised, by both parents and professionals, and that it may be more nuanced in its presentation than previously realised. The group brought together professionals (many of whom are also parent carers with lived experience of trauma) with considerable experience to discuss i) what parent carer trauma looks like and ii) how we can best support those experiencing it.

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* *We are using the term ‘parent carer’ to describe all parents of children with additional needs (such as leaning and developmental disabilities & health or physical conditions)*

CONTENT WARNING: This document refers to traumatic examples based on parent carers’ lived experiences. If you are concerned this may be distressing please ensure you have safe mechanisms around you to support you, such as talking to a trusted friend, taking a break from the topic when you need to or speaking to your GP or mental health professional.

Professionals can also be affected by vicarious trauma so ensure you have reflective time and space to gain support on these issues.

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Executive Summary

Aims of this paper

1. To raise **greater awareness** of parent carer trauma: what it can look like, how it may present, what causes it and how you can help
2. To **reassure parent carers** who are experiencing trauma that they are not alone and to help them realise the importance of receiving appropriate and timely support
3. To illustrate to policy makers, commissioners and funders how key it is to support this often neglected group and the **benefits of appropriate support** for the whole family

Parent carers

- **Parent carers** are an often unseen, unheard and unspoken about group of parents. They need to be recognised by professionals and policy makers for their **considerable resourcefulness and expertise** in caring for their children, but also as a group who need more support and recognition.
- The heavy demands that parent carers carry can take a serious **toll on their mental health** yet the focus on all those around them is often solely on the child.
- There are often **complex systems** around the family (education, health and social care) which can be supportive but can also be intrusive and add to the parental burden and cause **re-traumatisation**.
- **Trauma** this group may experience is often **overlooked or neglected** for a number of reasons. Trauma can be ongoing and cumulative rather than one single event. Where the child’s health needs remain constant, there may be no end point, no safe space and no chance of “post trauma” work.

Key points for professionals

- There is growing awareness of what **trauma-informed practice** looks like within health and social care. This needs to be applied to services that come into contact with parent carers so they can provide sensitive care and avoid exacerbating or even creating unnecessary trauma. **Trauma informed support needs to be holistic and supported from the top down.**
- How professionals relate to parent carers can have a significant effect on their wellbeing and ability to cope, both positive and negative. For example, how difficult news is delivered can stay with a parent for life and conversely, a supportive professionals may help a family get through a challenging period.
- Beyond this, professionals also need to know that **trauma symptoms amongst parent carers may show up in particular, and sometimes unexpected, ways**. Specialist training is required to build awareness about this and ensure that professionals can spot parent carer trauma and respond effectively. This needs to be prioritised at a policy level and backed up with funding.
- Trauma does not always include a ‘Big T’ event (e.g., a road traffic accident) that causes flashbacks/nightmares. It may include ongoing, cumulative ‘small t’ events.
- What may seem inconsequential to others (e.g. a report being lost, surgery cancelled) may be part of a **long list of challenges** faced by the parent.
- Trauma for parent carers is not always ‘post’. In fact it can be **Post, Present and Predicted for the future (PPPTSD**) (Finch, 2023). We would also question the use of the term ‘Disorder’ as many responses are understandable given the challenges experienced.
- At times traumatised individuals may display **strong emotions** (e.g. anger, sadness, helplessness) and it is helpful if professionals try to meet these difficulties with openness and support rather than defence or blame

- **Hypervigilance** may be justified where a parent is caring for a medically complex child and may be key in keeping the child healthy and alive
- Child trauma and parent trauma can be **bi-directional** (i.e. parent affected by child's trauma and vice versa)
- Relating to the parent **with compassion** can help foster a supportive relationship. This will help if you need to have difficult conversations in the future. If parents feel **safe and listened to,** they are better able to engage in constructive communication and may not always require further specialist support.
- There is further information on pages 6-8 that can be shared with parent carers.
- **It is essential that those supporting traumatised individuals are well supported themselves** (reflective space, supervision, conversation with a colleague).

Key points for policy makers, commissioners and funders

- Ideally there needs to be an **ecosystem of support** available to parent carers that encompasses the NHS, education, social care and third sector provision. Here are some points to consider when deciding how to structure or fund services around parent carers and their families:
  - **Psychological support** should be available to parent carers, not just at the point of diagnosis but **at any point when a parent carer might be struggling**. Referrals at key moments, including transition points (school transitions, adolescence, transition to adulthood) may be helpful and should be handled sensitively. Services should also be aware that different family members may need different things at different times (e.g., fathers, siblings, grandparents).
  - General 'point of entry' psychological services such as NHS Talking Therapies (formerly IAPT) may not always have adequate knowledge or flexibility to provide effective support to parent carers; there is a case for investing more in **specialist services** (within the NHS and third sector) and/or **specialist training** for professionals within universal services.
  - Parent carers should be able to access trauma-trained professionals who can offer **specialist, evidence-based trauma interventions**, e.g., EMDR or trauma-focused CBT, if they need to.
  - **Flexibility is important**—services need to be structured in a way that recognises that parent carers may have to reschedule appointments at short notice due to unavoidable circumstances (e.g., child being unwell or needing hospitalisation).
  - **A 'one-size fits all' approach is not effective.** Parent carers are not a homogenous group. Their experience will be affected by the particular needs of their child and by other challenges, such as relationship problems, that may be exacerbated by the pressures around their child's health. This complexity needs to be recognised and responded to—for example, sometimes individual therapy might be required but other times family or couple therapy might be more appropriate. It is also worth bearing in mind that different forms of therapeutic support will suit different people, based on personality, current situation and previous experiences, and an important element of supporting traumatised parents is to provide choice, empowerment and transparency. So, ideally services (or the 'ecosystem') might be structured and funded to offer an element of choice to meet these varying needs.
- The **caring role** played by parent carers is **invaluable** and **giving them proper support is in everyone's best interests.** In the absence of adequate support, the whole family will suffer and the risk of reaching a **crisis** will increase. This can cause enormous and often enduring distress to individuals, families and communities. It also involves much higher costs for the public purse. In contrast, early intervention can **save money, reduce suffering and give parent carers the recognition and support that they deserve** and which helps to make the demands of long-term care-giving more sustainable.

Key Information/Handout for parent carers

Key points for parent carers

- Some things that may happen in relation to your child (e.g., medical appointments, fighting for services, stigma in society) can be experienced as traumatic
- Many parent carers find they are dealing with difficult things on a daily basis, often with no one to talk to or who understands
- This does not mean you have failed – feeling distressed or traumatised can be an understandable response to an unexpected and stressful situation. There is no need to feel guilty or ashamed for feeling this way.
- Connecting with others who understand what you are going through, or have similar life experiences, can be healing (either face to face or online)
- Try to connect with those who make you feel safe. Although you may feel like withdrawing at times of trauma, this can lead to social isolation if done over a long period of time.
- You may find it helpful to seek professional support as well. If you are traumatised it is important that you receive help from people who are trauma-informed/trained so that they can provide appropriate support to meet your psychological needs.
- Despite the difficulties most parent carers do manage to live a positive and fulfilling life, even when things are challenging. There is hope that you will feel better, although ups and downs can be part of our life journey.
- Ensure you make time to support yourself, including engaging in activities that replenish you, such as relaxation techniques (e.g. breathing exercises, mindfulness or meditation) and basic self-care (such as getting enough sleep, exercising, eating healthily and only drinking alcohol or caffeine in moderation). Most people know these are important but often find it difficult to prioritise themselves or may feel guilty for taking time for themselves. Remember it is a vital part of your life to look after yourself.
- Try planning a fixed time of day for a fixed period when you do something for yourself. It can be as short as a half hour, and as simple as sitting with a cup of tea, but if it is a daily ritual then it can become habit.

Further information

You can seek emotional support from your General Practitioner. You might need to explain the traumatic nature of your experience to gain specialist trauma support, such as Trauma Focused Cognitive Behaviour Therapy (TF-CBT) or Eye Movement Desensitisation and Reprocessing (EMDR). Below we list organisations that signpost to, or provide, emotional support (e.g., counselling) for parent carers along with their own description of their services.

Affinityhub.uk

Affinityhub lists practitioners who work with parent carers and their children. The site also includes words of wisdom from other parent carers and recommended resources to support parents. We also send out quarterly newsletters with information on research, services and news to do with Parent Carer Wellbeing. You can sign up on the website www.affinityhub.uk

Birth Trauma Association

The Birth Trauma Association (BTA) supports all women who have had a traumatic birth experience, and partners who have witnessed a traumatic birth. It is estimated that, in the UK alone, this may result in 30,000 women a year developing Post Traumatic Stress Disorder (PTSD). Also, as many as 200,000 more women may feel traumatised by childbirth and develop some of the symptoms of PTSD. The BTA wants women to know that they are not alone. The website offers emotional and practical support to women and also their families. (www.birthtraumaassociation.org.uk)

London Accessible Psychotherapy & Inclusive Supervision (LAPIS)
LAPIS supports anyone affected by disability or life changing health issues by providing specialist counselling and psychotherapy for you, your family and carers. We offer regular appointments at a convenient time to make it easier to attend and have a fully accessible room, so anyone can benefit from our service. We offer our service on a sliding scale, which means that you pay what you can afford. Email us at info@thelapis.co.uk or use the contact form at www.theLapis.co.uk. A qualified mental health professional will get back to you.

Murmuration Community Therapy
Murmuration Community Therapy run nurture groups for parent carers living in Bristol and the South West and online. These are intimate online/in person circles of SEND parents, meeting for 8 weeks to find belonging, support and space to process the big emotions. Using compassion-focused approaches led by a qualified therapist, this course helps parents to stay emotionally well and find friendship with others on a similar path. After the course has finished, nurture groups are supported to continue meeting if they would like to, with half-day retreats and monthly drop-in sessions providing ongoing opportunities to keep connecting up with people who get it.

Spaces are free/by donation, and new groups start on a regular basis. If you would like to register your interest or find out more email: murmurationct@gmail.com

Rainbow Trust
When serious illness affects a child, family life is turned upside down and time becomes more precious than ever. Rainbow Trust pairs each family with a dedicated expert Family Support Worker to help them face and make the most of each new day. Families are overwhelmed with grief and worry about their child's illness and getting them to hospital appointments that may be hundreds of miles away, all the while trying to keep life as normal as possible for their other children. Our Family Support Workers support the whole family with whatever they need so that families don't have to manage alone. For more information click here (www.rainbowtrust.org.uk/)

Respond
Respond is a national charity providing therapy and specialist support services to people with learning disabilities, autism or both who have experienced abuse, violence or trauma. They provide a range of trauma-informed services for children, young people, adults and professionals. These include psychotherapy, advocacy and other support services which aim to prevent abuse and equip individuals and their families to come to terms with their experiences and live more positive lives. They also provide specialist training, supervision, reflective practice and consultancy to equip agencies and providers in developing and delivering trauma-informed services Family or individual therapy may be available.

Further information: https://respond.org.uk/
Tel: 0207 383 0700 Email: admin@respond.org.uk

Samaritans
Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope or at risk of suicide throughout the United Kingdom and the Republic of Ireland. https://www.samaritans.org/ Tel: 116 123

1. Risks to parent carer health

It is well recognised that parent carers can be at risk of poorer mental and physical health. This can be due to many factors, including coming to terms with their situation and the additional stressors in their life, such as navigating various systems (education, health and social care), lack of sleep, experiencing blame or not being believed, as well as stigma and discrimination.

It is not always acknowledged, however, that the parent may also be experiencing trauma. The Working Group explored the often interlinked and sometimes overlapping concepts and the difficulties in clearly defining subjective experience. This section therefore touches upon anxiety, depression, suicidality and physical health before exploring trauma in more detail.

a) Anxiety and depression

Compared to other parents, children with a developmental disability and their parents report more symptoms of mental health problems (Rydzewska et al., 2021), and poorer family functioning (Jackson et al., 2022).

Research highlights an increased risk of stress, anxiety, distress and depression in parent carers (Emerson, 2003). One study suggested that mothers of children with intellectual and developmental disabilities were about 1.5 times more likely than other mothers to experience depression (Singer, 2006).

Other difficult emotions such as guilt, shame, helplessness and hopelessness, a sense of loss, envy of other families and exhaustion are also reported (Griffin, 2019).

Of relevance to this paper, there is increasing evidence that post traumatic stress symptoms can be associated with the onset of depression, anxiety and sleep problems (Carmassi et al., 2021).

b) Suicidality

Carers – including parent carers – are a high risk group for suicide, with some groups of carers contemplating suicide at more than four times the rate of the general population (O’Dwyer et al., 2021). Research has shown that depression, feeling trapped in the caring role, using unhealthy coping strategies, and being in conflict with family and professionals are risk factors for suicidal thoughts and suicide attempts. For parent carers conflict with family and professionals can be a direct source of trauma, while depression and the use of unhealthy coping strategies can be signs of underlying trauma. Although more research is required to understand the link between trauma and suicide in carers, it is vital that suicide prevention is incorporated into routine services and support for parent carers.

c) Physical health

Further, parent carers often report poorer physical health (Bringing Us Together, 2018), with a build-up over time. Chronic stress has been found to increase illness and suppress the immune system (Lovell & Wetherell, 2017) as well as affect cognitive processes, such as memory (Lovell, et al, 2014).

Mind and body influence each other in both directions and positive emotional wellbeing is consistently linked to lower health risks and vice versa (Song et al., 2014).

General guidance on Supporting Parent Carer Wellbeing for Health, Education and Social Care Professionals is available here (www.affinityhub.uk) (Griffin, Johnston & Steeples, 2020)

2. What is Parent Carer Trauma and what might it look like?

The aim of the Parent Carer Trauma Working Group was to shine a light on parent carers' experiences and, where appropriate, consider the relevance of trauma. As a group we grappled with how to define it, what to call it and how it shows up. We were also keen to avoid 'concept creep' where an ever increasing number of factors can be included in a definition, thereby potentially diluting its meaning (Haslam, 2016).

We wanted to find a way of legitimising and capturing the enormity of parent carer distress and to help professionals and parents make sense of their experiences. While recognising that much of that distress is rooted in material (e.g., poor housing, inappropriate education settings) or social (oppression) causes. Therefore, this document should not be used as a tick box exercise to diagnose "parent carer trauma" and pathologise their distress. In fact we question the use of the term 'disorder' when referring to a parent's lived experience – often the responses of parent carers are understandable (and sometimes they are constructive coping strategies) given the context in which they are situated.

The Group discussed the symptoms of trauma that parent carers may present, including hypervigilance, increased anxiety, irritability, anger and social withdrawal. Parents may frequently visit the doctor, which could be viewed as hypervigilance but may also be justified while seeking support and answers regarding their child's condition. In contrast, active avoidance may involve disengaging from medical service as a way of protecting the parent from facing difficult truths or encountering further trauma (Carmassi et al., 2021).

Research suggests many parent carers experience traumatic events, both major events and smaller cumulative and ongoing traumas. These are referred to respectively as 'Big T' and 'small t' traumas (Griffin, 2021; Emerson, 2019).

Some examples are provided below - whether these are deemed 'Big T' or 'small t' will be based on the individual and there can be overlap between them.

- Birth trauma
- Receiving child's diagnosis
- Illness/disabilities that involve 'waiting for next episode' (justified hypervigilance), such as epilepsy or severe allergies
- Child behaviours described as challenging (e.g., child to parent violence)
- Secondary trauma of abuse of child in institution
- Life-threatening/limiting illness/condition; high risk medical procedures
- Being declined for specialist school/therapies/support which are viewed as vital for the child
- Being told that their child will never walk/talk/be independent
- Stressful waits for appointments in proximity of previous major Trauma
- Witnessing invasive medical procedures on child
- Having to repeat difficult histories
- Blamed by wider family/society for child's behaviours / diagnosis (e.g. autism not recognised in family)
- Recognition that child may not reach independence (it may take time to acknowledge this)
- Micro-aggressions due to ableism (e.g. Do Not Resuscitate orders placed on disabled people during Covid-19) or discrimination (disabled people and their families disproportionately affected by austerity and cost of living crisis)

A key aspect of the 'small t' traumas is that there can be little time in between to process them and move on before the next one comes along. In some cases, families cope with an immediate crisis but 'buckle under the cumulative strains of multiple, persistent challenges, in ‘a cascade effect’ (Walsh, 2016, p.317). This experience is referred to as a ‘pile-up of demands’ in the Family Stress model (Hamilton, McCubbin & Patterson, 1983). Something small can be the straw that breaks the camel’s back.

The cumulative impact of small ‘t’ traumas could be described as ‘weathering,’ a term that applies to any marginalised group and can be described as “the repeated or chronic activation of stress processes over years and decades—the measurable physiological stress you feel in the body [which] has both immediate and long-lasting consequences for physical health and longevity” (Geronimus, p 29). Given the chronic stress of many parent carers experience on top of social isolation, this concept may well be a helpful way to frame the high incidence of parent carer mental and physical health problems.

The Working Group suggested that trauma for parent carers can be multi-layered and multi-faceted.

In Griffin’s (2021) research parent carers reported that at times of severe stress some entered an altered state of awareness, which they referred to as a ‘zoning out’ and feeling ‘so calm’ in order to deal with a difficult situation. There was also a sense of parent carers being constantly ‘on edge’ and many referred to experiencing an ‘emotional rollercoaster’. These reports may connect to other symptoms associated with trauma: emotional numbing, emotional dysregulation, dissociation and negative alterations in mood. Furthermore, fight, flight, freeze, fawn or fragment responses are all possible in the face of repeated stress and trauma.

Distress can be expressed through anger and this may be turned inward (blaming oneself, decreased self-compassion) or outward (onto education, health and social care professionals). Some parents report that anger is motivating and helps in their ongoing battle for resources. However, where there is a loss of trust it can make the continued contact with professionals challenging (Blackman et al., 2022, p. 72).

Guilt and shame are commonly experienced by parent carers and these feelings have been found to be associated with higher levels of post traumatic stress symptoms in caregivers (Carmassi et al., 2021). Encouraging self-compassion is a key strategy for supporting wellbeing including in caregivers (Neff & Faso, 2015; Neff, 2023).

Parent carers can be affected by the different stages in their child’s life including: at diagnosis, if significant milestones are missed or delayed, transitions (e.g., to secondary school or to adulthood), when the child becomes physically larger / stronger than parent including those who are physically dependent on parents for transitioning, feeding and toileting. Trauma can even occur as early as pre-conception genetic screening, when a child is in utero and a scan reveals life limiting condition or diagnosis, or at birth when diagnosis is suddenly made.

Responses can sometimes be at surprising times, such as on returning home after a child leaves hospital after a period of time as an inpatient. It can be that the process of moving out of ‘survival mode’ can cause unprocessed traumatic feelings to surface. Returning home may evoke relief yet simultaneously parents may feel unsafe and unnerved because suddenly they do not have medical professionals around them to monitor their child and be available to answer questions. Therefore, in some ways, parents may feel that they have to be more vigilant, and as there can be a delay in receiving community services they may also feel more isolated (depending on their circumstances) - and the contrast between inpatient life and being back at home can be stark.

Diagnosis at later stages can also be problematic although some parents report that it can also be a relief if they have long suspected that their child was developing differently. Further guidance on giving a diagnosis is available from the MDU (2021), Patient (2024), and the Royal College of Nursing (2013).

> *‘Parents frequently described the delivery of bad news as being catastrophic’*
> *(Emerson, 2019, p.9)*

A significant concern that looms large for many parent carers is ‘who will look after my child when I am dead?’. Bonanno’s (2021) work on trauma identifies hope about the future as one of the three key tenets of the ‘flexibility mindset’ one needs to manage trauma effectively (along with confidence in our ability to cope and willingness to think about a threat as a challenge)[i]. For some parent carers this does not seem possible.

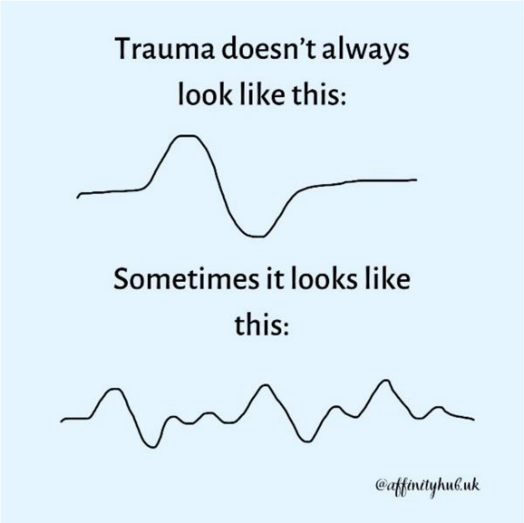


Table 1 provides some examples of what trauma may look like for parent carers.

- **Table 1 What trauma might look like for parent carers**

- A parent who experienced birth trauma having to regularly attend the same hospital, or similar, where the initial trauma happened. A father who witnessed his partner and child almost dying due to birth complications. Factors such as stressful waits for appointments, witnessing invasive medical procedures or having to repeat difficult histories can retrigger the initial trauma. Even seemingly small incidents (a report being lost) take on heightened sense of ‘risk’. For some parents birth trauma is compounded by how information about their child’s diagnosis or prognosis has been delivered.
- A parent whose child displays behaviours that challenge and is regularly hit at home. They feel ashamed and don’t share this with anyone. Help is not easy to access. The parents manage this by very rarely going out, they lose contact with friends and support networks. If they do share their experiences with others they can fear negative repercussions, either their child or their parenting capacities being seen in a negative light or fear of their child being “taken away” by social services (see Institutionalising Parent Carer Blame report by Cerebra, 2021).
- A parent is distraught by a child’s autism diagnosis and is shunned by the wider family (‘othering’) and blamed for ‘bad parenting’. Wherever they turn they feel ostracised and misunderstood. They start to believe that it is all down to them and

them alone to support their child and their mental health deteriorates. When combined with unsuitable housing, or with loud teenagers in gangs hanging around the front door adding to the autistic child's distress, parents can feel trapped and unable to ask for help. Over time the parent recognises that their child will not live an independent life which makes them realise the long-term implications of their situation

- Parent carers whose child has been abused in an institution (e.g. Winterbourne View) who were not offered professional help or an opportunity to collaborate with staff (Challenging Behaviour Foundation & The Tizard Centre, 2020). Some were also threatened with improper use of mental health legislation (Flynn, 2012).
- Many parents become battle weary due to the constant "fight" for services or respite and negotiating across complex appeal systems and multiple agencies. Sometimes the hard-fought-for service requires great effort to maintain on the part of the already exhausted parent. For example, finding suitable Personal Assistants (PAs), especially to cover short anti-social shifts, is becoming increasingly difficult in the current economic climate and some families lose their Direct Payments as a result. This can lead to despair, hopelessness and a sense of "giving up".
  NB: in theory PAs and Direct Payments exist to support disabled people and their families. In reality however, it can involve a lot of time dealing with bureaucracy and trying to find, interview, and employ people.
- Trauma can be cumulative rather than a one-off incident and when every day feels like a struggle events such as a local authority review of a child's transport to school can feel catastrophic. Many family lives are a finely balanced house of cards. Without that transport the parent's ability to work, get siblings to other schools in other parts of a city etc. can become impossible.
- A parent being asked to give their child's medical history in each new medical appointment and having to give detailed information over and over again. Parent may appear tearful or somewhat detached and it may not be obvious to the listener that the parent's behaviour is a survival response to the repeated trauma of repeated re-telling of past traumas.
- Chronic lack of sleep due to worry about their child's health or their child's own disrupted sleep pattern can have profound impact on parental mental health and in some cases, can lead to sleep deprivation psychosis. The shock of this acute experience can be traumatic.
- Uncertainty can compound trauma, either uncertainty about the child's diagnosis or prognosis or not knowing whether services might be available. Waiting times for genetic investigations, autism and ADHD diagnoses can range from months to years and the "not knowing" or not being able to access services until there is a diagnosis can feel unbearable. The lack of any explanation can lead some to blame themselves for their child's complex needs.
- Some parents can feel traumatised by a struggle to attune to their child. Some struggle to bond with their premature baby if the baby needs to be in an incubator and is hospitalised for long periods as a neonate. Some feel emotionally and practically detached from their baby and ashamed that medical professionals seem to have a closer bond. Some parents have feared bonding in case their baby dies and some have thoughts of infanticide, believing their baby might be "better off" dead than suffering. The ensuing guilt around these types of responses can be overwhelming. A child with complex needs who does not respond in expected ways can leave parents doubting their own parenting capacities and even their ability to love their child.

3. General definitions of trauma

Medical model and the Power Threat Meaning Framework

With all the diagnoses considered here we are mindful as a group of the risk of pathologising experiences when using definitions from the predominant medical model.

The medical model is defined as the approach whereby an individual's difficulties are located in the person themselves. Criticisms of the medical model are ubiquitous; however, the medical model will still be present in many services that parent carers access.

The Power Threat Meaning Framework (PTMF) (Johnstone & Boyle, 2018) may be of greater help in making sense of experiences. The Power Threat Meaning Framework re-frames peoples' responses to particularly difficult experiences as understandable, sometimes even helpful. The principles underlying the PTMF include the assumption that:

> 'what may be called psychiatric symptoms are understandable responses to often very adverse environments and that these responses, both evolved and socially influenced, serve protective functions and demonstrate human capacity for meaning making and agency.'

In relation to parent carers the PTMF (Dudley-Hicks, James & Morgan, 2023) could be relevant in the following way:

- Parents might commonly experience challenging circumstances throughout their lives including (but not restricted to):
    - Becoming estranged from friends and/or family,
    - The lack of well-funded, locally provided person centered support for their child's needs (or support more generally),
    - Being criticised, judged or devalued by professionals and wider society,
    - Witnessing their child being stigmatised, deliberately humiliated or in some cases abused by others,
    - Lowered immune system (e.g., chronic illness/pain) and/or exhaustion.
- These can threaten parent's ability to protect/nurture their child (and their wider family), access support for their child and themselves, gain a sense of financial security, develop a sense of belonging in wider society and feel effective as a parent.
- The way parents make sense of these experiences can have a significant effect on their wellbeing. For example, parents might feel powerless, helpless, silenced, inadequate (not a good enough parent), excluded, responsible, trapped and/or marginalised.
- Parents might experience unconscious (linked to the autonomic nervous system, e.g., fight/flight response) or conscious responses to these adverse circumstances.
    - They might experience anxiety, stress, dysregulated sleep, heightened arousal, hypervigilance, self-blame and/or self-criticism, become self-silencing, withdraw, 'give up' and/or strongly fight/advocate for their child.
- If, however, they are able to recognise they share similar levels of challenge with other parent carers, and are given the support they need to become empowered, they may be able to compassionately re-frame the meaning they make of their experience to one of resilience, self-love, and self-acceptance, rather than self-blame, and ultimately shame. This process can take time, requires reflective space, and at times, support from others.

- As it can be difficult to challenge current power imbalances, lack of awareness in society and daily struggles the process may require timely ongoing support and interventions.

However, as many professionals work under the umbrella of the 'medical model' and certain referral pathways are reliant on diagnoses we felt it would be helpful to outline the different diagnoses that may have relevance in order to raise broader awareness.

For more information on the PTMF, please visit bps.org.uk/power-threat-meaning-framework

Trauma responses in parent carers can resemble those of PTSD, but with some differences. To better understand these, it is useful to consider existing definitions and their relevance to the experiences of traumatised parent carers.

a) Trauma

While there is no single definition of trauma, there are some common elements.

The UK Government's working definition (https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice) of trauma informed practice (see more details on page 22) includes the original internationally recognised definition of trauma developed by the Substance Abuse and Mental Health Services Administration (SAMHSA) (2014):

> "Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening. While unique to the individual, generally the experience of trauma can cause lasting adverse effects, limiting the ability to function and achieve mental, physical, social, emotional or spiritual well-being."

SAMHSA (2014) highlight the importance of the 3 E's in their definition which recognises the individualised nature of trauma, the **event(s)**, how it is **experienced** and the **effects**.

The UK Trauma Council (https://uktraumacouncil.org/trauma/trauma) defines trauma as 'a distressing event or events that are so extreme or intense that they overwhelm a person's ability to cope, resulting in lasting negative impact.' Generally a traumatic experience 'has a seismic impact on the individual's worldview and emotional functioning' (Calhoun & Tedeschi, 2010).

b) PTSD

It is important to highlight that trauma is part of the human condition and most people will experience something traumatic in their lifetime. Post-traumatic stress is a common response to a traumatic event. It only becomes Post-traumatic Stress Disorder (PTSD) when the symptoms are severe and persistent for longer than a month and negatively interferes with a person's ability to function. **The majority of people do not go onto develop PTSD.**

As Bonnano states:

> *'Neither trauma nor PTSD is a static, immutable category. They are dynamic states with fuzzy boundaries that unfold and change over time… PTSD does happen... And sadly it is often debilitating. But an extreme reaction like PTSD does not simply come about instantaneously because of exposure to a trauma-inducing event.*

> *Violent or life-threatening events are undeniably difficult, and most people who encounter them experience at least some form of traumatic stress. They may feel stunned and anxious, for example, or struggle to manage disturbing thoughts, images, and memories. These reactions vary across people and events, and typically they are short-lived, lasting no more than a few hours or a few days, sometimes even a few weeks. In this transient form, traumatic stress is a perfectly natural response. But it is not PTSD.*
>
> *PTSD is what happens when traumatic stress doesn't go away, when it festers and expands and eventually stabilizes into a more enduring state of distress. But this outcome is not nearly as common as we might think.' (2021, p. 14)*

Post-traumatic Stress Disorder (PTSD) is a condition that may occur after traumatic events, life threatening events or painful experiences. PTSD includes these criteria.

- Re-experiencing a traumatic event, either through 'flashbacks' or in the form of dreams/nightmares — this is the most characteristic PTSD symptom.
- Negative self-perception (including feeling diminished, defeated, or worthless).
- Interpersonal difficulties or problems in relationships.
- Emotional dysregulation.
- Dissociation — where a person feels disconnected from themself and/or the world around them.
- Emotional numbing — where the person lacks the ability to experience feelings, feels detached from other people, gives up activities that they have previously enjoyed, communicates less with other people, has amnesia associated with significant parts of the event, or has persistent negative beliefs or expectations about themselves.
- Negative alterations in mood and thinking.
- Hyperarousal (including hypervigilance, anger, and irritability). May also manifest as self-destructive or reckless behaviour, exaggerated startle responses, insomnia, and difficulty concentrating.
- Avoidance of situations that trigger memories of the event. The person may avoid talking or thinking about the event by becoming absorbed in work or hobbies (NICE, 2022)

Further information from the:
- National Institute of Clinical Excellence (https://www.nice.org.uk/guidance/NG116)
- UK Trauma Council (https://uktraumacouncil.org/trauma/ptsd-and-complex-ptsd)
- NHS (https://www.nhs.uk/mental-health/conditions/post-traumatic-stress-disorder-ptsd/) Mind (https://www.mind.org.uk/information-support/types-of-mental-health-problems/post-traumatic-stress-disorder-ptsd-and-complex-ptsd/complex-ptsd/)
- PTSD UK (https://www.ptsduk.org/what-is-ptsd/)

c) Key information to consider on how parent carers' trauma might differ from PTSD

While some parent carers do meet the criteria for PTSD (Emerson, 2019) the Working Group noted that in their clinical and lived experience current diagnostic definitions do not always fully capture the experience of parent carers for a number of reasons:

> 1. Trauma for parent carers is not always 'post'. In fact it can be Post, Present and Predicted for the future (PPPTSD) (Finch, 2023)
>
> 2. There is not always a clear 'Big T' event that causes flashbacks or nightmares, rather there can be cumulative 'small t' events

3. It can be difficult to distinguish between some forms of chronic stress and trauma

4. Hypervigilance may be justified where a parent is caring for a medically complex child and may be key in keeping the child healthy and alive

5. Child trauma and parent trauma can be bi-directional (i.e. parent affected by child's trauma and vice versa)

The Working Group therefore broadened their reflections to consider other diagnoses and definitions that may relate to the experiences of parent carers such as i) Complex Trauma (C-PTSD), ii) Prolonged Duress Stress Disorder and iii) vicarious trauma.

i) Complex Trauma

In their study '6 clinical cases of trauma in families that have children and adults who have a learning disability and /or are autistic', Blackman et al. (2022) use the term 'complex trauma' to capture the experiences of their participants. This helps to highlight that trauma for this cohort does not always centre around a single event, rather there can be ongoing, cumulative trauma. Although complex trauma is often used in relation to early developmental trauma it can also include being in a life-threatening situation (in adulthood) from which you cannot escape e.g., slavery or torture.

The Diagnostic and Statistical Manual (DSM-V) does not currently distinguish Complex Post-Traumatic Stress Disorder (CPTSD) from Post-traumatic Stress Disorder (PTSD). In contrast the 11th version of the International Classification of Diseases (ICD-11) distinguishes two disorders; complex posttraumatic stress disorder (CPTSD) and PTSD. It is not possible to be diagnosed with both.

ICD-11 defines complex posttraumatic stress disorder (sometimes just referred to as complex trauma) as arising after exposure to an event or series of events of an extremely threatening or horrific nature, most commonly prolonged or repetitive events from which escape is difficult or impossible (for example, torture, slavery, genocide campaigns, prolonged domestic violence, repeated childhood sexual or physical abuse).

It was developed following observation that some individuals tended to experience more complex reactions extending beyond those typically observed in PTSD and which included effects in three key domains: emotion regulation, self-identity and relational capacities. Thus, in ICD-11, CPTSD is a disorder that includes not only the symptoms of PTSD but additionally disturbances in the three additional domains.

Complex trauma therefore involves **both** the three core elements or clusters of PTSD which are:

- Re-experiencing the traumatic event in the present
- Avoidance of traumatic reminders
- Sense of current threat

and:

- Disturbances in self-organisation that are pervasive and occur across various contexts
- Emotion regulation difficulties (for example, problems calming down)
- Negative self-concept (for example, beliefs about self as worthless or a failure)

Further information can be found in Cloitre (2020).

ii) Prolonged Duress Stress Disorder

'Prolonged Duress Stress Disorder' is an anxiety disorder resulting from prolonged exposure to stress. This is not included in the DSM-V. It has been proposed that it only differs from PTSD with regard to the absence of a 'traumatic event' (Marsh, 2003). It has been used to describe the stress involved in long term care for a relative (Scott, 2013) and may therefore be relevant to some parent carers. In particular, the cumulative and ongoing nature of stressors in some parent carers may fit with this concept.

iii) Vicarious trauma

Vicarious trauma is a term used to describe the emotional impact of repeated exposure to the traumatic stories and experiences of others. It can particularly affect professionals who provide empathetic engagement with trauma survivors. Generally, it involves indirect exposure to a traumatic event through firsthand accounts or narratives.

Witnessing and supporting your child through their own trauma and suffering may fall under the definition of vicarious trauma for parent carers. There can be a bi-directional impact of trauma (e.g., the child is affected by the parent's trauma and vice versa). This can also be the case for professionals working with parent carers and their families.

Of note is that vicarious growth has also been reported. (See below on Post Traumatic Growth p.24)

d) Avoidance of 'parent blame': Difficult parent or traumatised parent?

A key issue identified by the Working Group was the importance of avoiding pathologising trauma or locating it (solely) in the parent carer (as some sort of personal failure), but rather looking at it being an understandable response to their (often difficult) environment.

No parent carer is a blank slate and, as with all human beings, they will bring their own histories and experiences to their parental world. But while their past, or present situation, may make some parents more vulnerable than others it is key that parents are not blamed. For more information on parent carer blame see Cerebra (Cerebra, 2021). You can also read our article for the British Association for Counselling and Psychotherapy Children, Young People and Families journal here.

4. Treatment/support options for parent carers

While a diagnosis can be useful in gaining understanding, it is mainly helpful if it leads to appropriate support. There are a number of ways that parent carers and professionals who work with them can support parent carers who identify that they are experiencing/have experienced trauma.

A crucial starting point is for services to take care not to traumatise/re-traumatise parents and families (Blackman et al., 2022, Challenging Behaviour Foundation & The Tizard Centre, 2020). This includes how professionals communicate and relate to parent carers. Furthermore, ableist practices such as a lack of adaptations, negative narratives around disability and parent blame can all be experienced as 'small 't'' microaggressions which can unintentionally contribute further to traumatisation.

a) Phased support

Generally, a 3-phase approach (Herman, 1992) to supporting trauma is recommended. This involves:

1. Stabilisation (Safety and Competence)
2. Trauma processing (dealing with traumatic re-enactment)
3. Integration and mastery

Note that these are not always linear and there may be a looping back in between 1 and 2 in order to keep safe when processing the trauma. For some, the main focus may be providing 1 for a significant amount of time (possibly the life-time of the child). This is important and necessary ongoing work which is valuable in of itself.

b) Self-support

Parent carers can often identify potential solutions themselves and it is important that these positive, strengths-based skills are recognised and nurtured. For example, one family typed up the answers to questions asked at every hospital admission and shared this document at Accident and Emergency to avoid having to relive the story.

In Griffin's (2021) research, parent carers found positive others (e.g. partners, family, friends) helpful. However, when the people around them were not supportive it could become an additional source of distress. Professionals could also provide this support (if positive) as well as exacerbate problems (if negative).

To be considered positive, other people needed to provide sensitive, non-judgemental and compassionate support. Peer support could also develop a sense of belonging. These relationships can be described as providing 'social capital' (Furstenberg & Kaplan, 2007) which is defined as "the stock of social good will created through shared norms and a sense of common membership upon which individuals may draw in their efforts to achieve collective or personal objectives" (p.221). Support could be face to face or online.

In Griffin's (2021) research participants who had been through a shocking or traumatic time had several strategies they found helpful. Interestingly, some of these, such as social withdrawal, were not always helpful at other times, suggesting that trauma demanded unique responses. Although social connection and support is an important part of trauma recovery, when those around the parents did not provide a 'safe space' parents would withdraw. Social withdrawal could help protect participants from i) the risk that other people would fail in their attempts to support them and ii) seeing further disturbing things about their child or other children with similar difficulties. Quotes are provided below from parent carers (Griffin, 2021).

> *'I'm very careful with who I talk to because you are emotionally so vulnerable that you don't have the resilience to sort of bat off the stuff that's unhelpful.' – Parent Carer*

These findings suggest that a crisis may not always be the best time to access a support group or be made to face the reality of a situation as, for some people, this could be overwhelming. Furthermore, some found connecting online helpful while others felt exposed to further upsetting material which could re-trigger their own trauma. Strategies such as limiting social media usage or leaving particular parent carer groups helped.

The participants reflected that sometimes nothing helped except time; as one commented:

> *'I was completely in shock. And I'm not sure that anything anyone would have done would have helped me. You have to go through that unfortunately.' – Parent Carer*

Other themes included:

- *Survival mode*
  A few participants described their way of coping in a crisis as going into 'survival mode' and 'firefighter mode', after which they would move on but not necessarily make time to recover from or process what they had been through. These experiences then may be at risk of remaining unprocessed and re-arise at future points.

> *'I was very isolated because I couldn't go out, I couldn't expose my child to frightening things, he was running in main roads and taking me with him… I had to lock all the doors and hide the keys, so I think I just got through… my coping mechanism of a really hard time is once it's gone is that my brain goes, okay, memory wipe, it's almost like trauma, you know, when you've experienced something traumatic, you don't afterwards remember a lot of what you did or how you did it.' – Parent Carer*

- *Faith*
  Some parent carers found it helpful to turn to their beliefs in times of crisis. Participants found that sitting in the hospital chapel and praying comforting and 'like the only constructive thing I could do'. However, others found their faith challenged.

- *Safe, quiet space on your own*
  Several participants spoke of needing a safe, quiet space on their own to centre themselves. As one said "[I am] better on my own [then I] just feel calmer"

> [On receiving child's diagnosis] *'I was meant to go to work and I rang the manager and said I can't actually. I can't help anyone, I just can't give anything to anyone, so she gave me the day off and I went and bought this duvet and just sat under it. I think that day I just followed my guts. I just didn't need to think. It was a very visceral kind of reaction that I had… it just kind of cuddled me in a way that you probably get from if you were young and went to a parent. It was just comfort. Go into a cave and hide. And process it…' – Parent Carer*

Services who have contact with parent carers who are experiencing and/or have experienced trauma should be trauma-informed, sensitive and understanding. Recognising that traumatised individuals can respond in wide-ranging ways and meeting the person where they are with the support they need, *at that moment,* is crucial.

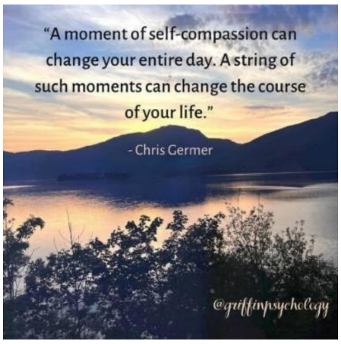
Traumatic or shocking events could also lead to change, including solution-finding and new perspectives but this could be difficult, take time and require a supportive and reflective environment. Becoming empowered and knowledgeable about their child's condition and the system could help mitigate against stress. However, this was also acknowledged as exhausting and at times overwhelming.

c) Professional support: What is currently available

Different approaches and models of therapeutic support will suit different people, based on personality, current situation and previous emotional support. An important element of supporting traumatised parents is to provide choice, empowerment and transparency – all key aspects of working in trauma-informed ways.

> *'Trauma-informed services recognize the need for the whole family to be given time and attention. It is crucial that parents receive the support that they want and need when they are ready (not what and when suits the system) to reduce feelings of helplessness.'*
> *(Emerson, 2019, p. 13)*

Furthermore, professionals can play a key role in ameliorating parent carer guilt and self-blame and encouraging them to develop a self-compassionate stance. Studies have suggested that self-compassion may play a significant role in well-being for parent carers (Neff & Faso, 2015; Neff, 2023).



'In a study on self-compassion in parents of autistic children the researchers found that those parents with more self-compassion perceived less stress when dealing with their children. They were less likely to be depressed, and more likely to be hopeful and satisfied with their lives. In fact self-compassion was actually a stronger predictor of how they were doing than the severity of their children's autism. This suggests that what's more important than the intensity of the challenges you face in life is how you relate to yourself in the midst of it.' - Dr Kristin Neff

We are aware of a number of models of support that parent carers have accessed and offering a choice of treatment options can be helpful for parent carers:

i) Talking Therapies/IAPT & Primary Care Mental Health services across the UK

The first port of call for many people in emotional distress is often an NHS Talking Therapies for Anxiety and Depression service (formerly know as Improving Access to Psychological Therapy (IAPT)) (England) or primary care mental health service (across the UK) or via their GP. While this may be helpful for some people, others report that it does not meet the very specific needs of parent carers.

In one study (Griffin, 2021), parent carers who sought emotional support reported that (IAPT) did not meet their needs due to:

i) *Inflexible appointments and criteria*. Parents reported being discharged part way through their allotted number of sessions because they missed a session when their child was in hospital due to illness or for major surgery
ii) *Non-specialist staff* who do not understand the complex impact of parenting a disabled child. For Parent Carers the practical and emotional aspects of wellbeing are often deeply intertwined so having someone who understands the context is

important. This is particularly pertinent for carers who are experiencing thoughts of suicide or infanticide (S. O'Dwyer, personal communication, 3rd November, 2023)

The Working Group highlighted that a referral to IAPT for trauma is not normally appropriate. Ensuring the suitability of the service is key to any referral, as if parents do not get the right support they can be even more traumatised as they feel they are a 'hopeless case' that no one can help. In Blackman et al., some parents experienced the systems around them as 'hostile or indifferent to their needs' (2022, p. 72) which can lead to a repeated cycle of difficulties.

A short-term counselling service may look at strategies to change the stressors. Obviously for parent carers often the stressor cannot be removed (i.e. the child's diagnosis or inadequate services or resources) so other ways of managing are necessary. The adjustment process may require ad-hoc emotional support alongside the other demands on the parents' psychological resources.

ii) Cognitive Behaviour Therapy

Trauma Focused CBT is recommended by NICE Guidelines and may be beneficial for some parents in certain circumstances. CBT can help parents to challenge unhelpful thoughts and behaviours and provide a clear pathway of support.

There were some suggestions that it may not be appropriate for all, though. Blackman et al.'s (2022) paper states: 'Short-term interventions, such as solution focused cognitive behavioural therapy…was often not appropriate for the enduring anxieties and stress experienced by families. Such approaches are generally manualised, and parents stated that they did not experience their specific difficulties being listened to and addressed.' (p. 73) Furthermore, additional pressures (e.g. homework) can add to the already overwhelming emotional load the parent is carrying.

For carers experiencing thoughts of suicide or infanticide, CBT is unlikely to be helpful (S. O'Dwyer, personal communication, 3rd November, 2023).

iii) Eye Movement Desensitisation and Reprocessing (EMDR)

Also, recommended by NICE guidelines, EMDR is a procedure that uses different phases to treat post traumatic stress disorder. The approach is underpinned by the idea that traumatic memories may become stuck and need help to be processed and stored in a way that is not detrimental to the person's functioning. By activating the memory and bilateral stimulation the client is assisted to create new, more adaptive neural pathways.

Jane Steeples, Psychotherapeutic Counsellor in the NHS shares her own practice in this area in a blog here (www.affinityhub.uk/blog/parent-carer-trauma-and-emdr) and notes:

'Whether trauma is from the past, more recent or an interplay between the two, EMDR is a strengths based approach. The first phase focuses on developing resources and stabilisation before directly addressing trauma. Many parents benefit from reconnecting to long forgotten skills or positive parenting experiences. It helps to take into account the wider societal and political context of people's experiences, helping to move away from pathologising individuals by recognising the discriminations and microaggressions routinely experienced by disabled people and their families, sometimes by the very systems they have come to rely upon. It helps if EMDR therapists have an understanding of the social model of disability and some awareness of the complex systems parents need to negotiate.'

Those with complex experiences may need a higher number of sessions and to be delivered flexibly acknowledging the other demands on the parent carers' resources (e.g., time, financial and psychological resources).

iv) Psychotherapy/Counselling

Both short and long term therapy may be helpful for parent carers who are traumatised and it is important that such support is tailored to the client. The Working Group comprised practitioners from different professional orientations (including integrative, relational psychodynamic, cognitive-behavioural, person-centred, narrative, family systems and coaching). Many of the professionals represented in the working group have different ways of formulating, making sense of and working with distress but ultimately all felt that it needed to be tailored to the individual in the context of a trauma-informed stance, flexible to their circumstances with a compassionate and collaborative relationship at the heart.

There is not always an easy or simple "protocol" that can be developed for supporting parent carers, which is why having psychotherapeutic practitioners who specialise, and are experienced in, this area is so important. Some parents find irregular, on-going access to support helpful, and need therapists who are willing to be indefinitely available 'every now and then' for top-ups. This can go against the more traditional view that therapy should involve regular sessions concluded with a defined 'ending' and is reflective of the longer term nature of the stress and trauma parent carers can live with.

The Working Group identified examples of organisations using different psychological therapies to support parent carers (e.g., Respond, LAPIS) which are listed in the parent carer handout on page 6-7 of this document. For example, Blackman et al. (2022) provided a 12 week extended therapeutic assessment and later continued in longer-term therapy following the assessment. Further organisations and professionals are listed on the Affinityhub.uk website.

Outcome measures

A list of outcome measures that can be used when working with parent carers is included in **Appendix II**. Using outcome measures can be helpful, not just for practitioners, but also for clients. Tools which highlight areas of change, as well as risks, can be an integral part of professionals' practice. Professionals may feel more competent to use these after undergoing appropriate training.

d) Trauma Informed Approaches

Trauma-informed practice is being increasingly developed across various settings (Office for Health Improvement and Disparities, 2022; SAMHSA 2014; NHS Scotland 2021). It is influenced by neuroscience, psychology, social science and attachment and trauma theories (NHS Scotland, 2021). It is a movement that originally came from the US and has trickled down into UK practice. Perhaps the most popular document comes from SAMHSA (2014). Although this was developed in the US in relation to substance abuse and mental health, it is a versatile document that is intended to be adapted to various settings. Scotland produced their own trauma-informed toolkit in 2021 (NHS Scotland, 2021) followed by Wales in 2022 (Public Health Wales NHS Trust, 2022). The Scottish & Welsh documents have incorporated SAMHSA ideas amongst others and adapted them to their communities. For the sake of this document, we will utilise the ideas developed by SAMHSA (2014).

What is trauma-informed practice?

Trauma-informed practice differs from trauma specific services (although it can include them). There are 6 principles of trauma-informed practice:

1. Safety
2. Trust
3. Choice
4. Collaboration
5. Empowerment and
6. Cultural consideration.

Trauma informed practice is a whole system approach embedding key trauma principles into organisational culture. It includes an organisation's ability to reflect on its role in historic contributions to the trauma of others and the ongoing impact of this. Trauma informed practice includes committing to adequately resourcing appropriate support.

SAMHSA (2014) suggest "4 R's" of trauma informed practice. The whole system has a **realisation** about the widespread nature of trauma and understands how trauma can impact on people and systems. People in the organisation are able to **recognise** the signs of trauma in people**.** The organisation **responds** by applying trauma-informed principles to all areas of service delivery. Finally, it seeks to **resist re-traumatisation** of clients as well as staff.

Trauma trained professionals

Because of how common trauma may be amongst the parent carer population, it was recommended that those supporting parent carers should be trauma trained in order to avoid further harm.

Traumatised individuals have two main requisites:

- The need for physical, psychological and emotional safety through trustworthiness and transparency
- Opportunities to build a sense of control and empowerment through choice, collaboration and equality

The point was reiterated that professionals need to be mindful that they do not traumatise, or re-traumatise, parents in the way that they communicate and relate and that they find ways to ensure the parents' voice is heard. Trust is a key ingredient in trauma informed work and making sure this is embedded throughout practice can take time and commitment to develop.

Of note in therapeutic trauma work is the delicate balance of being 'client-led' but also ensuring safety and not rushing the work in processing trauma for parent carers. At times practitioners may need prescriptive, practitioner-led anxiety management strategies to support the work (Bullock, 2020).

Members of the Trauma Working Group felt it could be useful to other professionals to share where they had received trauma training, including: PESI, European Society for Traumatic Stress Studies, Beacon House, Carolyn Spring, Confer and Make Birth Better.

Reflective practice for professionals

The Working Group emphasised the importance of professionals receiving appropriate support themselves: ***It is essential that those supporting traumatised individuals are***

well supported themselves (e.g., having a reflective space, supervision, peer support). This is at the heart of trauma-informed practice (SAMHSA, 2014). There are some reflective practice prompts in Appendix I.

Remember that vicarious trauma (page 17) is possible when working with traumatised individuals so taking time to actively consider your own wellbeing and pacing (i.e., not working with severely traumatised individuals in back-to-back appointments) and integrating regular practices for energy management, processing and regulation is key.

5. Post traumatic Growth

Following post traumatic stress some individuals also report, over time, posttraumatic growth. The concept of post-traumatic growth (PTG) (Joseph, 2013), which is linked to meaning making, refers to the positive change some individuals report after experiencing adversity.

Reflecting findings in the PTG literature, it is notable that one study reported that mothers 'reporting higher levels of caregiving demand for their child with intellectual disability also reported more personal growth and maturity' (Hastings et al., 2002, p.273). The dynamic nature of this process was illustrated by Cadell et al. (2014) who found that a caregiver's wellbeing influenced the meaning they made in an adverse situation and this, in turn, contributed to PTG: 'having a child with more severe disabilities may provide mothers with more opportunities to grow personally and to develop a mature outlook on the world because of the increased challenges posed' (p. 125). This point overlaps with the suggestion in the general coping literature that the 'more distressed the person is, the more meaning-focused interventions boost positive affect' (Folkman, 2011, p. 457).

The Positive Gain Scale (PGS; Pit-ten Cate, 20031) is a seven-item measure originally developed to assess parental perceptions of positive aspects of raising a child with a disability. Sharing this scale more widely can offer a positive narrative, and sense of hope, for parent carers which can counter the negative narrative that often exists around disability.

1. Since having this child I feel I have grown as a person
2. Having this child has helped me to learn new things / skills
3. Raising this child helps putting life into perspective
4. Since having this child, my family has become closer to one another
5. Since having this child, my family has become more tolerant and accepting
6. Since having this child I have become more determined to face up to challenges
7. Since having this child I have a greater understanding of other people

However, Young, Shakespeare-Finch and Obst (2020) note that growth can probably only occur in earnest 'after the person is coping successfully, or managing well enough that they are not preoccupied with merely surviving' (p. 632). The literature also states that PTG is not inevitable (Tedeschi, Shakespeare-Finch, Taku & Calhoun, 2018) and, while professionals should be attuned to its possibility, it should be used with caution 'so as to not "expect" growth in parents, as [this] could place blame on parents who report no growth or rewards from their experience' (Young, Shakespeare-Finch & Obst 2020, p. 648).

Furthermore, parent carers may dip in and out of positive feelings, or recognition of growth, in an oscillating process. Professionals providing emotional support can help parents as they experience the ongoing process of 'reorienting' and finding balance' by framing this response as understandable (see further information on this process in Griffin & Gore, 2023 https://doi.org/10.1111/jar.13098, Griffin, 2021).

6. Other point discussed

a) Personalised support

Parent carers are not a homogenous group and will have other intersecting identifies that can affect their wellbeing. For example, increased microaggressions due to their ethnicity or cultural background (as well as parenting a disabled child) can create a double discrimination and potentially increased risk of trauma.

Furthermore, parent carers may be experiencing other challenges, such as marital problems and domestic abuse, potentially made worse by the reaction to their child's diagnosis. If the supporting professional fails to recognise the complexity of the situation they may refer parents to support with limited understanding (e.g. purely for marriage / relational difficulties).

The Working Group noted that timing is key for trauma support and focusing on stability and safety is necessary before the trauma can be processed. There can be long waits for NHS emotional support. However, if support is not timely the situation can be exacerbated by experiences that retrigger and build on the initial trauma. This has been referred to as a 'chain reaction' that captures the 'ongoingness' of trauma where appropriate support is not forthcoming (Ioannou, 2023, p. 153). In this way it can be helpful to think of trauma as 'experience' not only as 'an event'.

Where the NHS is not able to provide support third sector organisations may pick up referrals but they require appropriate funding to do this.

'UK services may serve to compound distress' (Emerson, 2019).

Parents may be reluctant to seek support, or find it hard to know how to get it. Referrals at key points, such as diagnosis, teenage years or transition to adulthood may be helpful. This needs to be done sensitively and different family members may need different things at different times (e.g., fathers, siblings, wider family such as grandparents).

Sometimes formal therapeutic support is not required, rather the parent carer just needs a sensitive, empathic response from a professional already in the life of the family to acknowledge their experiences. Furthermore, people need flexible, adaptive support which they can access as and when.

b) Couple work

Couple work can assist parents to discuss feelings about their child in a safe and supported way. Some parents want to protect their partner from how they are really feeling and this can lead to emotional distancing and misunderstanding. However many tensions come about because services routinely involve only the primary carer, often the mother, in appointments and specialist parenting courses which can lead the other parent feeling left out and deskilled as a parent of a child with complex needs. Inconsistent co-parenting and relationship tensions can ensue and negatively impact the child. Services need to be offered equally to both parents in order to reduce the risk of relationship breakdown and enhance consistent, skilled co-parenting.

It can be helpful if therapists are flexible in offering evening appointments (once the child is in bed) or online (so both parents can join even when one is at work).

7. Benefits of appropriate and timely emotional support

Psychological benefits

There are psychological benefits to both parents and families in engaging with trauma-informed support. Empowering parents and increasing strategies for self-care and coping can help the whole family, including better outcomes for the disabled child and their siblings and possible prevention of family breakdown. By supporting parents to retain other roles and identities (e.g., work/study or engaging in their own interests) their quality of life may also improve – by leading meaningful lives rather than just surviving.

Providing emotional support for parents will inevitably help in other areas too: fewer visits to the GP, reduced number of prescriptions, less crisis-level support when parents reach breaking point and being better able to support their child's needs. Parents who have processed their emotional responses are less likely to make unrealistic demands of services and more likely to adjust expectations and engage, in a pro-active way, with their new situation. Further, healthier parents are less likely to engage in unhelpful behaviours.

Cost benefits

There are likely significant cost benefits too. For example, it is estimated that the wider costs of mental health problems to the UK economy are around £117.9 billion per year – approximately 5% of gross domestic product (GDP). This prevalence of diagnosed mental health conditions also impacts the UK's labour force, including increased days of sick leave. Further information available from the Mental Health Foundation.

Furthermore, the Suicide Prevention: Interim Report estimates the cost of each suicide as £1.7m (Department of Health and Social Care, 2017). Most of this cost - around 70% - is the emotional impact on families and on society. The national cost of suicide is almost £10 billion a year. Suicide is not an individual problem.

Conclusion

The Working Group believe that professionals can play a significant role in supporting parent carers by recognising potential trauma and avoiding adding to the trauma burden. Professionals can acknowledge the sometimes overwhelming situations in which parent carers find themselves and help encourage self-support and self-compassion. It can be very powerful to remind a parent that it is not selfish to consider their own needs and it may be the first time a parent has heard it from a professional.

Relating to parents in non-judgemental and non-pathologising ways can often be healing for those who feel isolated. Where appropriate, professionals can refer for specialist support that is personalised to the parent carer.

Professionals also need to remember to look after themselves to avoid vicarious trauma when working with traumatised individuals and families.

We hope that by raising awareness of potential trauma in parents of children with special educational needs and disabilities it will lead to greater understanding and sensitivity from services and professionals thereby helping parent carers feel more seen and less alone.

We welcome feedback from any parent carers or professionals on this document and any suggested amendments or additions.

Please contact us via the Affinityhub.uk website.

References:

Blackman, N., Vlachakis, K. & Anne, A. (2022). Brief report on six clinical cases of trauma in families that have children and adults who have a learning disability and/or are autistic, *Tizard Learning Disability Review, 27*, 2, 69-77

Bonnano, G.A. (2021). *The End of Trauma: How the new science of resilience is changing how we think about PTSD.* Basic Books: New York

Bringing Us Together (2018), *Parent Carer Health: The impact of the caring role.* https://bringingustogether.org.uk/parent-carer-health-the-impact-of-the-caring-role/;

Bullock, P. (2020) Is counselling enough to treat trauma? *Therapy Today, 31*(3), 31-35

Cadell, S., Hemsworth, D., Quosai, T. S., Steele, R., Davies, E., Liben, S., Straatman, L. & Siden, H. (2014). Posttraumatic growth in parents caring for a child with a life-limiting illness: A structural equation model. *American Journal of Orthopsychiatry*, *84*(2), 123-133. https://doi.org/10.1037/h0099384

Calhoun, L. G. & Tedeschi, R.G. (2010) *Facilitating Posttraumatic Growth: A Clinician's Guide,* Routledge: Oxfordshire

Cantwell, J., Muldoon, O.T. & Gallagher, S. (2014). Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities, *Research in Developmental Disabilities,* 35 (2014), 2215-2223.

Carmassi, C., Dell-Oste, V., Foghi, C., Bertelloni, C.A., Conti, E., Calderoni, S., Battini, R. & Dell'Osso, L. (2021). Post-Traumatic Stress Reactions in Caregivers of Children and Adolescents/Young Adults with Severe Diseases: A Systematic Review of Risk and Protective Factors, *International Journal of Environmental Research and Public Health,18,* 189.

Cerebra (2021). Institutionalising Parent Carer Blame by Luke Clements and Ana Laura Aiello. https://cerebra.org.uk/research/institutionalising-parent-carer-blame. [Accessed 19th September 2023).

Cloitre, M. (2020). ICD-11 complex post-traumatic stress disorder: Simplifying diagnosis in trauma populations. *The British Journal of Psychiatry, 216*(3), 129-131. doi:10.1192/bjp.2020.43

Challenging Behaviour Foundation and the Tizard Centre (2020). Broken: The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required. https://www.challengingbehaviour.org.uk/news/broken-report/

Dudley-Hicks, D., James, G. & Morgan, G. (2023). Using the Power Threat Meaning Framework to make sense of experiences parenting a child diagnosed with a learning disability: An exploration of fit and utility - Summary for participants. *Researchgate.* October 2023.

Emerson, A. (2019). 'Room of Gloom': Reconceptualising Mothers of Children with Disabilities as Experiencing Trauma. *Journal of Loss and Trauma,* DOI: 10.1080/15325024.2019.1658946

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. Journal of Intellectual Disability Research, 47, 385-399.

Emerson, E., McCulloch, A., Graham, H., Blacher, J., Llewellyn, G. M., & Hatton, C. (2010). Socioeconomic circumstances and risk of psychiatric disorders among parents of children with early cognitive delay. American Journal on Intellectual and Developmental Disability, 115, 30-42.

Finch, E., Griffin, J., Yakeley, M., Bonger, N. & Villierezz, P. (2023). No child is an island: The context for trauma in parents of children with Special Educational Needs and Disabilities (SEND), *BACP Children Young People and Families Conference*, 18th March 2023.

Flynn, M. (2012). “South Gloucestershire safeguarding adults board”, Winterbourne View hospital. A Serious Case Review, available at: http://sites.southglos.gov.uk/safeguarding/adults/i-am-a-carerelative/winterbourne-view

Folkman, S. (2011). *The Oxford Handbook of Stress, Health and Coping.* Oxford: Oxford University Press.

Furstenberg, F.F., & Kaplan, S.B. (2007). Social capital and the family. In M. Richards, J. Scott, & J. Treas (Eds.), Blackwell companion to the sociology of families (pp. 218–232). London: Blackwell Publisher.

Geronimus, Arlene T. *Weathering: The Extraordinary Stress of Ordinary Life on the Body in an Unjust Society.* London: Virago. 2023.

Griffin, J. (2019). A report into the Emotional impact of parenting a disabled child. March 2019, *Researchgate*, DOI: 10.13140/RG.2.2.15565.08169 (also on www.affinityhub.uk)

Griffin, J. (2021). *Day by Day: Emotional Wellbeing in Parents of Disabled Children,* UK: Free Association Books

Griffin, J., & Gore, N. (2023). ‘Different things at different times’: Wellbeing strategies and processes identified by parents of children who have an intellectual disability or who are autistic, or both. Journal of Applied Research in Intellectual Disabilities, 1– 8. https://onlinelibrary.wiley.com/doi/10.1111/jar.13098

Griffin, J., Johnston, E. & Steeples, J. (2020). Supporting Parent Carers’ Emotional Wellbeing: Guidance for Health, Education and Social Care Professionals. https://bit.ly/3F2N73k

Hamilton, I. McCubbin & Joan M. Patterson (1983). The Family Stress Process, *Marriage and Family Review, 6*(1-2), 7-37. DOI 10.1300/J002v06n01_02

Haslam, N. (2016). Concept Creep: Psychology’s Expanding Concepts of Harm and Pathology. *Psychological Inquiry, 27*:1, 1-7.

Hastings, R. P., Allen, R., McDermott, K. & Still, D. (2002). Factors Related to Positive Perceptions in Mothers of Children with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 269-275.

Herman J. L. *Trauma and recovery. From domestic abuse to political terror*. London: Harper Collins; 1992. [Google Scholar]

Ioannao, A. (2023) Existential Theoretical Foundations on Trauma and Implications for the Therapeutic Encounter, *Existential Analysis,* 34.1, pp 145-160.

Jackson, S. Z., Pinto-Martin, J. A., Deatrick, J. A., Boyd, R., & Souders, M. C. (2022). High Depressive Symptoms, Low Family Functioning, and Low Self-Efficacy in Mothers of Children With Autism Spectrum Disorder Compared to Two Control Groups. Journal of the American Psychiatric Nurses Association, 10783903221104147.

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System. *Journal of Humanistic Psychology, 0*(0). https://doi.org/10.1177/0022167818793289

Joseph, S. (2013). *What doesn't kill us: a guide to overcoming adversity and moving forward*. London: Piatkus.

Keenan, B.M., Newman, L.K., Gray, K.M. & Rinehard, N.J. (2016). Parents of Children with ASD Experience More Psychological Distress, Parenting Stress and Attachment-Related Anxiety, Journal of Autism and Developmental Disorder, (46), 9.

Lovell B, Wetherell MA. The cost of caregiving: endocrine and immune implications in elderly and non elderly caregivers. Neurosci Biobehav Rev. 2011 May;35(6):1342-52. doi: 10.1016/j.neubiorev.2011.02.007. Epub 2011 Feb 17. PMID: 21333674.

Lovell, B., Elliot, H., Liu, C.C.S & Wetherell, M. (2014). Memory failures for everyday tasks in caregivers of children with autism. Research in Developmental Disabilities, 35(11), 3057-3061.

Marsh, C. (2003). A Psycho-Physiological comparison of Post-Traumatic and Prolonged Duress Stress Disorders. *Behavioural and Cognitive Psychotherapy*. 31, 109-112

MDU (2021). https://www.themdu.com/guidance-and-advice/guides/breaking-bad-news

Neff, K. D., & Faso, D. J. (2015). Self-compassion and well-being in parents of children with Autism. *Mindfulness, 6*(4), 938–947. https://doi.org/10.1007/s12671-014-0359-2

Neff, K. (2023) Self compassion for caregivers. https://self-compassion.org/self-compassion-for-caregivers/ and https://www.youtube.com/watch?v=jJ9wGfwE-YE [Accessed 26th September 2023}

NHS Scotland (2021). Trauma-Informed Practice: A Toolkit for Scotland. Trauma-Informed Practice: A Toolkit for Scotland (www.gov.scot)

NICE (2022). Post Traumatic Stress Disorder. https://cks.nice.org.uk/topics/post-traumatic-stress-disorder/diagnosis/diagnosis/

O'Dwyer, S.T., Janssens, A., Sansom, A, Biddle, L., Mars, B. Slater, T. Moran, P. Stallard, P., Melluish, J., Reakes, L., Walker, A., Andrewartha, C. Hastings, R.P. (2021). Suicidality in family caregivers of people with long-term illnesses and disabilities: A scoping review, *Comprehensive Psychiatry, 110*, 152261, ISSN 0010-440X, https://doi.org/10.1016/j.comppsych.2021.152261. https://www.sciencedirect.com/science/article/pii/S0010440X21000390

Patient (2024). https://patient.info/doctor/breaking-bad-news

Pit-ten Cate, I. M. (2003). Family adjustment to disability and chronic illness in children Doctoral thesis. England, UK: University of Southampton. From Cerebra.org.uk: https://cerebra.org.uk/download/positive-gains-scale/#ref1

Public Health Wales NHS Trust (2022). Trauma-Informed Wales: A Societal Approach to Understanding, Preventing and Supporting the Impacts of Trauma and Adversity. Trauma-Informed-Wales-Framework.pdf (traumaframeworkcymru.com)

Reid, C., Gill, F., Gore, N. & Brady, S. (2016). New ways of seeing and being: Evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour, Journal of Intellectual Disabilities, 20(1), 5-17.

Royal College of Nursing (2013). Breaking Bad News: Supporting parents when they are told of their child's diagnosis. https://rcni.com/keywords/breaking-bad-news

Rydzewska, E., Dunn, K., Cooper, S. A., & Kinnear, D. (2021). Mental ill-health in mothers of people with intellectual disabilities compared with mothers of typically developing people: a systematic review and meta-analysis. Journal of Intellectual Disability Research, 65(6), 501-534.

SAMHSA. (2014). SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach.

Scott, M. J. (2013). Prolonged duress stress disorder. *CBT for Common Trauma Responses.* SAGE Publications Ltd, https://dx.doi.org/10.4135/9781473915046

Singer, G. H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. American Journal on Mental Retardation, 111, 155-169.

Song, J., Mailick, M.R., Ryff, C.D., Coe, C.L., Greenberg, J.S. & Hong, J. (2014) Allostatic load in parents of children with developmental disorders: Moderating influence of positive affect, *Journal of Health Psychology*, 19, 2, 262-272, p.263

Tedeschi, R.G., Shakespeare-Finch, J., Taku, K., & Calhoun, L.G. (2018). *Posttraumatic Growth: Theory, Research and Applications*. New York, NY: Routlege.

Totsika, V., Hastings, R.P., Emerson, E. et al. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability, *The Journal of Child Psychology and Psychiatry*, 52:1 (2011), pp.91-99.

Walsh, F. (2016). Family resilience: a developmental systems framework, *European Journal of Development Psychology*, *13*(3), 313-324.

World Health Organization. *International Statistical Classification of Diseases and Related Health Problems (11th Revision)*. WHO, 2018.Google Scholar

Young, S. Shakespeare-Finch, J. & Obst, P. (2020). Raising a child with a disability: a one-year qualitative investigation of parent distress and personal growth. *Disability & Society, 35*(4), 629-653. DOI: 10.1080/09687599.2019.1649637

Appendix I **Reflective practice exercise**

If you are a practitioner supporting parent carers take some time to reflect on the questions in the table below.

If you are a parent carer you may like to think about your own situation and what you've experienced as traumatic and how this affects you in different ways (e.g., how you communicate and behave, who you turn to for support). What do you need practitioners to know in order for them to support you?

NB: If this exercise brings up difficult feelings you may wish to explore this further with a mental health professional, or trusted colleague or friend.

Reflective practice for practitioners Think back to an interaction you've had with a SEND parent carer in your own practice or wider life. Briefly note down the details of the interaction. Drawing on anything you know about their situation, map out three possible challenges that might have been impacting that parent, (e.g., no sleep, struggle with services, child's distress, response of services etc.) Underline anything that could have been experienced as traumatic by this parent.

Now reflect on your own situation. Are there assumptions you may have made? It can be helpful to reflect on your own biases, which we all have, and how that may influence decisions made or how we view a family. Consider different factors such as disability, ethnicity, socio-economic status, culture.

What support do you need in order to best support the parent carer?

How can your work environment help you? (e.g., supervision, further resources for peer support, change in practice procedures, training)

Further informtaion on supporting parent carers is available here. https://www.tacinterconnections.com/images/Guide-to-Support-Families-of-Children-with-Complex-Needs.pdf

It is essential that those supporting traumatised individuals are well supported themselves (e.g. reflective space, supervision, conversation with a colleague). This is at the heart of trauma-informed practice. Reflective practice can bring up difficult emotions in all of us but can be very important in providing better support.

Appendix II Outcome measures

Using outcome measures can be helpful, not just for practitioners, but also for clients. Tools which highlight areas of change, as well as risks, can be an integral part of professionals' practice. Professionals may feel more competent to use these after undergoing appropriate training.

Trauma scales

The *International Trauma Questionnaire (ITQ)* (Cloitre et al., 2018) can be used for complex trauma and C-PTSD. Working Group members felt that this measure seems to capture how multiple traumatic events impact parents' self-concept, self worth/esteem and relationships.

Dissociative Experiences Scale-II (DES-II) (Carlson & Putnam, 1993) can be useful if dissociation or early developmental trauma is indicated.

The *Impact of events* scale (Horowitz, Wilner & Alvarez, 1979) lists difficulties people sometimes have after stressful life events. Although this may be relevant for some parents members of the working group felt that as it only measures one off events it is not always appropriate.

The *PTSD Checklist 5 (*PCL-5) (Weathers et al., 2013) is a 20 item self-report measure of the 20 DSM-5 symptoms of Post Traumatic Stress Disorder (PTSD). Included in the scale are four domains consistent with the four criterion of PTSD in DSM-5: Re-experiencing (criterion B), Avoidance (criterion C), Negative alterations in cognition and mood (criterion D) and Hyper-arousal (criterion E).

The *Posttraumatic Diagnostic Scale (PDS-5)* (Foa et al., 2013) a 24-item self-report measure that assesses PTSD symptom severity in the last month according to *DSM-5* criteria.

The *Trauma and Loss Spectrum – Self Report (TALS-SR*) (Dell'Osso, 2008, 2009) includes questions focused on losses and upsetting events that may have been experienced in your life at any time, and your reactions to them, even if it was a long time ago.

The *Clinician-Administered PTSD Scale for DSM-5 (CAPS-5)* (Weathers et al., 2013) is a 30-item structured interview that can be used to: i) Make current (past month) diagnosis of PTSD, ii) Make lifetime diagnosis of PTSD and iii) Assess PTSD symptoms over the past week.

For children: *The Children's Revised Impact of Event Scale (CRIES)* is a brief child-friendly measure designed to screen children at risk for Post-Traumatic Stress Disorder (PTSD), developed by the Children and War Foundation (Perrin et al. 2005). The tool is designed for use with children aged 8 years and above who are able to read independently.

Other measures that may be of relevance to parent carers

The *Positive and Negative Affect Schedule (PANAS-SF*) (Watson, Clark & Tellegen, 1988) is used to assess positive and negative affect.

The *Depression, Anxiety and Stress Scale - 21 Items (DASS-21*) (Lovibond & Lovibond, 1995). is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress.

The *Patient Health Questionnaire 9 (PHQ*-9) is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders. The PHQ-9 is the depression module which has been validated for use in primary care. It is not a screening tool for depression but it is used to monitor the severity of depression and response to treatment.

The *Generalised Anxiety Disorder Assessment (GAD-7*) is a self-administered patient questionnaire used as a screening tool and severity measure for generalised anxiety disorder.

The *Parenting Daily Hassles Scale* (Crnic and Booth,1991) use statements to describe a lot of events that routinely occur in families with young children which sometimes make life difficult. These experiences can be relevant to parent carers.

Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978 a short version of the Parental Locus of Control Scale, (Campis, Lyman and Prentice-Dunn, 1989) is a commonly used scale to measure levels of self-efficacy.

The *Perceived Stress Scale* (Cohen et al., 1983) is a commonly used instrument for measuring the perception of stress.

The *Warwick-Edinburgh Mental Well-being Scales (WEMWBS*) (University of Warwick & university of Edinburgh, 2006) were developed to enable the measuring of mental wellbeing in the general population and the evaluation of projects, programmes and policies which aim to improve mental wellbeing

The *CORE Outcome Measure (CORE-OM)* (Evans et al., 2002) is a self-report measure of psychological distress designed to be administered during a course of treatment to determine treatment response. The client is asked to respond to 34 questions about how they have been feeling over the last week, using a 5-point scale. The scale covers four dimensions: i) Subjective well-being, ii) Problems/symptoms, iii) Life functioning and iv) Risk/harm

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