



Supporting Parent Carers’ Emotional Wellbeing

Guidance for Health, Education and Social Care Professionals

‘This is your job but this is our life.’

– Parent Carer

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Guidance for Health, Education and Social Care Professionals on supporting Parents of Children with SEND and/or ALN*

Section	Page No.
Key points	3
1. Introduction	4
2. Context	4
○ Disability	
○ Diversity, Culture and Inclusion	
○ Family System	
3. Diagnosis	7
The Education System	9
4. Emotional responses	10
5. What parent carers need: Combining practical and emotional support	14
○ Human, compassionate relationships	
○ Holistic and co-ordinated services	
○ Responsive and flexible services	
○ Empowerment and Collaboration	
○ Sharing the Load	
○ Time for themselves	
6. Emotional support: Helping professionals to help parent carers	16
○ Understanding distress	
○ A chance to talk	
○ Further support	
○ Your own emotional needs as a professional	
7. Conclusion	19
What does SEND/ALN mean?*	20
Who this guidance is for	20
Acknowledgements	20
Glossary	20
References	23

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Key points

- Parent carers can feel an array of different emotions in relation to their child's disability and the support services around the family
- Good support is possible. At times, however, services can exacerbate the stress on families rather than alleviate it
- Our prior beliefs, assumptions, values and culture influence how we make sense of our current situation. Acknowledging this within ourselves, as professionals, as well as for the families we support, can help us work towards meaningful outcomes for the whole family
- Diagnosis can have a positive and negative impact on the family. It should not be seen as an end point as support should be available at the point of need
- Diagnosis does not define a child, they are still a unique, complex individual
- Understanding the system in which parents find themselves (health, education and social care) can be overwhelming at times and they may need help to navigate it
- Parents may experience positive and negative emotions, sometimes all at the same time. They commonly report:
 - Gaining a wider perspective on life
 - Greater compassion and understanding of others
 - Developed expertise and awareness
 - Joy and pride in their child's achievements
 - Closer and more valued relationships

As well as feeling:

- Angry
 - Anxious, stressed or feeling 'on edge'
 - Depressed or Low Mood
 - Guilt about their child's diagnosis or difficulties
 - A sense of loss
 - Shocked or traumatised by their experiences
- Parents find it helpful when services demonstrate the following attributes:
 - Compassionate, human relationships
 - Holistic, co-ordinated, responsive and flexible – including emotional and practical support
 - Empowerment and collaboration
 - Sharing the load
- Professionals can help parent carer wellbeing in the following ways
 - Understand distress
 - Offer a chance to talk
 - Consider ways to provide group & practical support
 - Signpost to further emotional support
 - Consider your own emotional needs

1. Introduction

Parents of children who have special education needs or disabilities (SEND)ⁱ or additional learning needs (ALN) (parent carers) commonly report both a positive and negative impact on their own emotional wellbeing. This guidance is for professionals working in the Health, Education and Social Care fields and focuses on how you can support emotional wellbeing in parent carers as part of your role as well as acknowledging that parental wellbeing has a key influence on child wellbeing. An important aspect of support is gaining a fuller understanding of the family's perspective and context as well as recognising the complex emotions they may be experiencing.

Undoubtedly being a parent carer can bring additional stressors into the life of the family. Some of these are due to the child's impairment itself but the majority are in relation to the context in which families suddenly find themselves. Families will generally have more services and professionals in their lives with the aim of bringing extra support and expertise. At times, though, this also has the potential to create more conflict, invasion of privacy, feelings of vulnerability and judgement.

'the thing about parents of disabled children is that we can't hide our vulnerability, we're so vulnerable, because professionals are constantly wanting to know what our child had for breakfast and wanting to know how they are going to the toilet' – Parent Carer

The charity *Contact*, for families with disabled children, say that in the UK there are around 1 million disabled children under the age of 16, which equates to one child in 20. They suggest that '72 per cent of families with disabled children experience mental ill health such as anxiety, depression or breakdown due to isolation'ⁱⁱ. The practical challenges and stress of caring for a disabled child sometimes cause difficulties in the network around the parent, including tensions with friends or within families.

Along with a potentially negative impact on relationships and practical issues, such as finances or housing, families can also experience stigmaⁱⁱⁱ and discrimination in society^{iv}. Further, parents often report poorer physical^v ^{vi}, as well as mental, health. The practical and emotional struggles for families with a disabled child are often deeply intertwined, which can lead to a pile-up of demands that would test the personal resources of any individual. Despite the emotional impact on the parent the focus for many professionals is solely on the child^{vii}.

Although many parents have positive relationships with professionals, some families report that the way members of the public, professionals and services interact with them can be damaging. This includes experiences of:

1. Being undervalued and excluded from discussions and activities central to their child's life
2. Feeling judged, criticised, mistrusted or patronised
3. Being perceived as difficult or challenging

Alternatively, some families have had an absence of support due to a variety of reasons or errors which then results in crisis point being reached.

2. Context

As well as considering the context of the families you support it is useful to reflect on your own position, in terms of beliefs, culture and values. Developing greater awareness, not only on an individual level but also across the team, encourages co-production with parents

and therefore more meaningful outcomes for families^{viii}. User-led training and feedback, including family questionnaires, can ensure all perspectives are considered and services meet the needs of the family rather than providing a one-size-fits-all approach.

Disability

It can be helpful to be familiar with the Social Model of Disability which was developed by disabled people in response to an overly medicalised view of disability. The Social Model of Disability highlights that whilst the impairment can be a challenge it is often the environment that is disabling. Rather than treating everyone the same, it is about allowing everyone full access and removing unnecessary barriers that cause the inequality. For example, if a disabled person who cannot use the stairs wishes to access a building that has a step at the front, it is the building and lack of adaptation that disables them.

As with professionals, parents will come with their own experience and assumptions. Sometimes there may be a discrepancy between the parent and professional perspective requiring an empathic and sensitive approach. Alongside reflective practice, in order to enhance understanding in this area, it can be helpful to read first person accounts by parent carers and people who are disabled.

Another useful exercise is to create your own cultural genogram with a disability focus^{ix}. Cultural genograms^x are similar to a family tree but include consideration of our wider cultural influences, as well as family, such as school, religion, class and ethnicity. Reflecting on our views and assumptions about disability and where they came from can help to reveal unconscious biases. When you consider your own relationship with disability you can ask yourself: what does disability mean to you? What are your assumptions? Have you had personal experience of disability or is the lived experience largely unknown? Being honest about any internalised fears or prejudices about disability can help to dissipate them and to avoid defensive practice. Cultural genograms encourage reflection on our own and other people's cultural identities that can help expand our cultural competence. They can be done individually or within team building and group supervision contexts.

Diversity, Culture and Inclusion

Professionals benefit from considering how aspects of our social or political identity affect the lives of families with a child with SEND/ALN. People bring their own interpretations and perspectives based on their ethnicity, culture, faith and other different factors (see Social Graces model^{xi}).

Takiwatanga - the Maori word for autism. It translates as 'In his/her/my own space and time'^{xii}

A report produced by the National Autistic Society on the challenges for families affected by autism from Black, Asian and Minority Ethnic Groups identified 'key challenges, including difficulties in getting a diagnosis, low awareness of autism and child development, a culture of stigma, shame and blame in some communities, family denial and isolation of parents and carers, language and communication barriers, and difficult communication with professionals, often due to families' lack of confidence or professionals' attitudes'.^{xiii}

'I felt that we were being judged and I felt that if you don't know my culture you don't know the things that are important to us. You haven't been in my shoes. ... I think that is down also to under-representation of certain people within that kind of field as well. So the lack of understanding of what might motivate me to engage...and in the end I just felt it was a waste of my time. And I stopped attending quite abruptly.' – Parent Carer

This can affect access to support and create a double discrimination^{xiv} of overlapping or intersecting social identities as part of wider systemic inequalities. It is also recognised that there can be a 'double burden' when families who face the most adversity also are less likely to have the financial resources to provide a buffer^{xv}.

Factors such as being a single parent, same-sex parent or step parent may also raise specific challenges that professionals need to bear in mind. Furthermore, parents may have their own learning, neurodevelopmental and/or mental health needs which require support and sensitivity from professionals.

There are also personal preferences for receiving and making sense of new information. For some parents they may prefer to have written guidance to digest in their own time. For others they find it helpful to talk it through over a longer period of time. It is important to consider the different ways people learn and where they are in their disability journey.

'I think we all learn in different ways and I learn better by talking to people and experiencing things, rather than masses of reading.' – Parent Carer

Family System

It is helpful to think of the family as an inter-connected system. Each person within the system may bring different strengths, challenges, views and approaches; at times this can cause tension.

Relationships can be tested when there are additional pressures. There is a slight increase in the number of separations amongst parents of disabled children but with the right support this is by no means inevitable. Some parents report their relationships becoming closer.

Research suggests that fathers may find it particularly hard to find support and have expressed frustration with the lack of father specific services^{xvixvii}. There is also little research focused on fathers and how they cope; some evidence suggests that they might have different experiences to mothers^{xviii xix} which may influence the type of support they require.

Siblings can be affected in different ways: experiencing their needs as coming second; missing out on certain aspects of childhood (e.g. playdates) or having their sleep disturbed. There can also be benefits for siblings, sometimes acknowledged more as an adult, that they develop greater understanding and tolerance of difference and a broader perspective of life. There is further information on supporting siblings from the charity Sibs^{xx}.

Wider family can react in a variety of ways – sometimes helpful to the parent carers and other times less so. Grandparents may be as affected as the parents in coming to terms with their grandchild's disability, but this struggle is rarely acknowledged or support provided^{xxi}. While this means they can really understand the situation, it can also lead to a 'double grief' watching their own child's struggles over the grandchild's condition^{xxii}. At times it may help if professionals are able to speak directly to wider family to explain the condition or answer questions and this may alleviate some of the pressure on parents.

Parents will have different tensions in managing the family dynamics and professionals can help by recognising that a child with SEND/ALN does not exist in a vacuum. Supporting the whole family system will inevitably support child outcomes.

3. Diagnosis

The process of diagnosis is emotionally complex and often exhausting for parents. It is helpful for professionals to exercise patience and realise that diagnosis is not a singular event, rather it can be a long term adjustment process. Diagnosis does not define a child or their family, even when it seems all consuming or when services organise their access criteria or interventions around diagnoses. Whatever their diagnosis the child and their family are still unique, complex human beings.

Parents will try to make sense of their experiences - for their child and the family as a whole. This may take time and involve several different steps or stages.

'I was in total denial and I was depressed and I was crying a lot and I think that's why then someone from Child and Adolescent Mental Health Services (CAMHS) came in ...that's how everything started and I think, when she was explaining, at the time, I didn't understand what autism is and then after that I started reading and buying books.' – Parent Carer

Positive aspects of diagnosis

A diagnosis can provide a useful framework for understanding a child and their differences. It can validate parental concerns, which may have previously been dismissed by others as overly anxious parenting. Sometimes it gives the parent confidence and trust in their own parenting instincts, especially if they have long suspected that their child was finding something challenging. They can feel empowered to seek information, support and understanding from others.

Diagnosis may also help parents to let go of some of the guilt or blame if they had previously thought that their child's behaviour or developmental delay was due to a problem with their parenting. Guilt often continues in the lives of parent carers, though, and this is considered further in the next section.

Having a name to describe the child's difficulties can help the whole system around the child adjust and empathise. It may open up avenues of support and resources.

Negative aspects of diagnosis

The length of time it takes to achieve a diagnosis can be problematic, though. It can take many months or even years for diagnosis, either due to limited resources and awareness or because the condition is very rare and cannot be easily identified. During the wait there is little access to support for parents so behaviours that challenge or parental isolation may increase at the point when there is the most uncertainty.

Some children never receive a diagnosis despite observable developmental delay. Delays in diagnosis, or never receiving a definitive answer, can create particular difficulties and anxieties for parents of which professionals should be mindful.

As we've already noted for some families receiving a diagnosis is a relief. For many though it can provoke difficult responses such as:

- Initially, it can be a shock as the long term nature of the child's condition can no longer be denied and the hope that 'they will grow out of it' diminishes. How the news is delivered can have a long term affect on how parents view and cope with the information.^{xxiii}
- Diagnosis can make demands on parents to change the way they view and parent their child. It can also change their view on society or wider perspectives on life and

the human condition. While this can have a positive affect in the longer term, it can be a difficult transition. Couples or estranged partners might have different opinions around how much to adjust their approach and how to parent their child.

- With a diagnosis comes the uncertainty of who to share this information with – the child, siblings, wider family, school, peers – and how to manage all of the different responses they will have.
- Dilemmas around who and how to tell others can be particularly acute in cultures where there is a high degree of shame and stigma around disability. Some cultures have no words for certain conditions, which adds to difficulties navigating inclusion in that community or explaining the diagnoses to wider family members.
- Diagnosis can raise fears about the future: who will look after my child after I have gone? What prejudices and discrimination will my child face? Where will they go to school? Will they get a job? Will they ever have a partner? Although the majority of parents adapt and manage these concerns, at first they can feel overwhelming.
- Some diagnoses can seem subjective as research and understanding is ever evolving. For example, in recent years the presentation of autism in girls has become better understood and diagnostic criteria have adjusted as a result. This subjectivity can lead to mistrust and differences of opinion between professionals and parents (and between professionals). Parents who question diagnosis, or lack of it, can be viewed as ‘in denial’ rather than having valid concerns.
- Sometimes the diagnosis is not the one expected by parents. Parents often actively research potential conditions prior to receiving a formal diagnosis and begin to formulate their own ideas. If their research does not match that of the professionals, this can lead to tensions and disagreements.
- Sometimes children receive multiple diagnoses, which is particularly confusing, or they change over time. There is the risk of children’s abilities being underestimated because they have been given a particularly broad diagnosis. Parents should be reminded that regardless of the diagnosis they should not assume anything about their child purely based on a label

‘remember a diagnosis is an opinion not a prediction.’ – Parent Carer

- Sometimes parents do not fully understand a diagnosis so it needs to be explained clearly, especially when there is a spectrum of how a child with a particular diagnosis may change and develop. Parents will use online resources to research information and its important that professionals prepare parents for what they might read, ensuring they have accurate information and do not fall prey to misinformation.
- Diagnosis does not always open the door to resources, with some parents finding no post-diagnostic support or ongoing support services are available in their area. Sometimes support is recommended and referrals put in but parents do not know (or have the required energy) that they may need to chase these up when they do not receive any further information about the referral.

‘the referral we had from his diagnosis was ‘here’s a leaflet’ and that was it’ – Parent Carer

- It is also important that professionals do not hold up a diagnosis as an end goal and only focus. Implementing support at the point of need (in line with the SEND Code of Practice^{xxiv}) requires immediate action while awaiting diagnosis. Often a diagnosis – especially if the condition was correctly suggested - does not change the interventions in place, e.g. autism friendly strategies. These can be tweaked or changed if necessary. However sometimes parents are encouraged to see a

diagnosis as a solution and end point which will “solve” the problem. This is far from the truth and this realisation brings further challenges.

Other issues to consider around diagnosis

Learning about a diagnosis can lead parents to question whether they or other family members might have the same condition. In some cases this may lead to the parent getting diagnosed which can sometimes mean a greater understanding and support. However, for some people, genetic conditions that are passed down can provoke feelings of ‘genetic guilt’.

Parents need to be given hope about the future along with clear, realistic information about what the diagnosis means. This requires an informed and compassionate response from the professional and clear signposting on where to go for further support. Ideally this would include, at least, a follow up appointment, telephone call or personalised letter.

The Education System

As well as the health and social care systems, families of children with SEND/ ALN are also likely to have a greater direct involvement with the education system than many families. This may feel supportive, but at times may feel like a series of mini battles. There are likely to be some differences of opinion or perspective along the way about the nature of the child’s needs, as well as the best way to offer support. Such differences of perspective can feel challenging for all concerned. It is important for professionals to keep in mind that they are on the ‘same side’ as the family and to be mindful of the ongoing emotional toll that can be caused by a perception of conflict.

Multi-disciplinary meetings can be daunting for families. This is more than a professional meeting for the family and has a far higher emotional impact than it does on professionals. With time pressures, it can be difficult to avoid meetings feeling ‘business-like’. As with all interactions, efforts to ensure the meeting feels emotionally safe are worthwhile. Keeping ourselves in a calm, socially engaged state supports this state in the people around us^{xxv}, with tangible benefits to avoiding defensiveness.

For some children in England, a decision will be made to apply for an Education, Health and Care Plan (EHCP). This will involve collating evidence for the EHCP, long periods of waiting, and assessments to determine whether a Plan will be issued and what the content will be.

The application for an EHCP includes clear explanation of a child’s needs. The experiences of some families may be that this feels akin to needing to justify that their child requires additional intervention or support. This can be emotionally demanding as the process highlights the myriad challenges of the child in a way that can feel overly negative.

As a professional writing about a child, there is likely to be more than one reader of any report. There will be times when clear explanation of need is required for SEND processes. People who have never met the child may be asked to make decisions about funding based on the explanation within reports. Professional reports may also be used to support teachers and teaching assistants to offer intervention.

Families, and at times the child, will also read the report. The way we speak about children and the words we write matter^{xxvi}. Similar to with medical diagnoses, SEND processes may guide professionals towards the use of labels and categorisation. Although assessments may yield different results on different days, the terms used in professional reports may be perceived as ‘truths’ about the child. The words we use to describe children may be remembered by families for longer than we remember them ourselves. We can keep this in mind and write with respect.

In Wales the Additional Learning Needs and Education Tribunal (Wales) Act 2018 will replace the current Special Educational Needs (SEN) framework with a reformed system based on Additional Learning Needs (ALN). The Act makes provision for universal, statutory Individual Development Plans for all children and young people with ALN.

The Act will bring an end to the current distinction between school led interventions and local authority issued statements and integrates the separate legislative arrangements that exist for pupils in schools and post-16 students in colleges. The Act seeks to improve collaboration between local authorities and health boards and establish a fairer and more transparent system with greater emphasis on disagreement avoidance and dispute resolution.

4. Emotional responses

The emotional impact of parenting a child with SEND can be far reaching and complex. Parental emotions may vary due to the ebb and flow of the caring role and related demands. Someone may be falling apart one day due to lack of sleep and coping and asserting their rights to support the next. This does not necessarily need to be pathologised, rather it is an understandable reaction to an unexpected situation requiring management of numerous demands. There may be different experiences for mothers and fathers, often linked to mothers having greater caring responsibilities and role conflict. Although every individual is unique there are some common emotional responses which may impact positively or negatively on the individual and those around them. Several of these are considered in more detail below.

Parents often report positive gains from having a child with SEND/ALN including personal growth^{xxvii} and learning to put life into perspective. It can lead to an openness towards the world, appreciating what is really important and giving a renewed sense of purpose. Individuals become more compassionate and understanding of others in a similar situation.

Parents develop greater expertise and awareness, becoming more solution focused and confident in their ability to not only support their child, but also help others in a similar situation. These skills can transfer over to other areas of their life. Maternal positivity is also found to be associated with child outcomes and suggests the potential for intervention and support^{xxviii}.

Relationships (new and old) may gain greater significance, in particular with those who truly understand the new circumstances families find themselves in. Parents experience enormous pride and joy in the child's achievements, however comparatively small, delayed or different they may seem to others.

Parental reports of positives are not as well recognised in the academic literature as the negatives although this is changing more recently with a move away from the predominantly negative narrative.

Conversely the negative impact on parental wellbeing is well recognised^{xxix} including psychological distress^{xxx}, stress, depression and chronic sorrow^{xxxi}. Parents may be in denial, feel angry, helpless, traumatised and commonly fearful of what the future holds for their child^{xxxii}. Awareness of this array of different responses may help manage professional - parent interactions. Although it is important to note that not all parents will experience these.

Anger

Recent statistics released by the Disabled Children's Partnership^{xxxiii} show that only 4% of parent carers feel they get the right support to safely care for their disabled child. This may, in part, explain why some parent carers feel angry and, at times, this can be directed towards professionals and services.

Anger can come out as a generalised irritability and increase in loss of temper in situations not even directly connected with the upsetting situation. Rather than perceive anger as parents being 'aggressive' or 'difficult'^{xxxiv} it can be helpful to remind ourselves of the parents' perspective, their current situation or frustrations and consider ways in which we can enable them to feel heard and supported.

Anxious, stressed and feeling 'on edge'

The most commonly reported parental response is that of stress, anxiety or worry. Parents report a constant feeling of being 'on edge'; illustrated, in different ways, in the first author's research:

- Worrying over provision for their child and even current support feeling precarious as the battle over services continues in perpetuity
- Managing behaviours that challenge and the impact on the wider family
- Feeling 'on-call' even when their child is at school (or at respite). Unable to engage in other activities in case they receive a call to come and collect their child
- Feeling unheard or judged by services
- Experiencing stigma and discrimination including where children have a hidden disability and the perception and judgement of others is problematic and limiting

'if you go on a train and you get the looks and you just think there needs to be more awareness out there. Acceptance. Not everybody is the same.' – Parent Carer

Having a heightened sense of vigilance or alertness can make parents nervous, sensitive and feel under attack. Even everyday requests, such as a child's homework, can be experienced as an additional demand too many.

Denial

Denial may be helpful for some parents in the beginning but can become problematic if left over time. One way of coping is to shut out unwanted or unexpected information and this may allow the parent to keep going in their everyday life.

It is a delicate balance for professionals to give the accurate, informative advice they need to in a manageable way that does not overwhelm the parent. Giving written information that parents can access at a later date may be useful in allowing them to read in their own time. For others though it can be useful to ensure they understand what you are telling them to avoid missed opportunities for support and intervention.

If a parent appears in denial on first hearing that their child could be experiencing difficulties, it's important to recognise that this is a changeable state and care should be taken to avoid labelling them as a parent 'in denial'. The work of Achievement for All^{xxxv} and the SEND Code of Practice suggests that a gradual building of trust through conversations between professional and parent is important, and this would be more effective in bringing parents towards acceptance – however, as often, children need the label in order to access the support.

Depression or Low Mood

Parent carers may feel depressed or low in mood. Depression includes symptoms such as continuous unhappiness, difficulty finding joy in activities that were previously enjoyed as well as lethargy and sleep problems.

Depression is more common in parent carers than in the general population, in fact studies have suggested mothers of children with intellectual and developmental disabilities are about 1.5 times more likely than other mothers to experience depression^{xxxvi}. This implies it is reactive in response to the situation in which parents find themselves.

At times of low mood people may be more likely to withdraw from others just when they need social support. Encouraging parents to meet with other special needs parents or groups may be useful as well as seeking out appropriate emotional support if necessary, i.e. talking therapies.

Guilt

Parents can feel guilt over many different aspects of their life - their struggles to adhere to a daily therapy programme or the impact on the wider family. It is a primal instinct to protect one's child and keep them from harm. When your child faces challenges it can bring up feelings of guilt which may seem irrational to the outside world.

If there is no diagnosis, or limited understanding of what a diagnosis means, then parents may search for alternative meaning including blaming themselves because the uncertainty becomes unbearable. By feeling guilty it takes back some control for the parent, however inappropriately.

'People often use the strategy of blaming themselves to protect their cherished beliefs about the controllability, predictability and justice of the world. By blaming themselves they are able to hang on to their beliefs. (After all, if I am to blame, I could have prevented the [traumatic] event from happening. If I could have prevented it from happening, then my sense of control is maintained.)'^{xxxvii}

Professionals can help ameliorate these feelings by acknowledging them and clarifying the complexities of cause and effect in relation to special needs, i.e. we cannot control our genes; many causes are unknown or have numerous different variables the majority of which we cannot influence.

Emphasising that there is no such thing as 'perfect' parenting may also help; we cannot prevent all difficulties in our child's life and some form of adversity is an inevitable part of existence. 'Good enough'^{xxxviii} parenting is sufficient.

Loss

When something unexpected happens in your life, and things do not go the way you thought they would, it can be experienced as a form of loss. The way that people adjust and adapt can be very personal. Professionals should be wary of putting a fixed, linear framework around how parents feel and remain flexible and responsive to the individual.

Some people may compare it to a grieving process but this is not the reality for others. There are subtle and tangible differences. Love and gratitude for their child are to the fore, so grief, where present, may linger in the background making it hard to reflect upon without feelings of guilt. Another contrast is that rather than a singular 'event' there may be many

throughout a child's life that disrupt the family unit and require adjustment; what Langridge refers to as 'little deaths'^{xxxix}. This might mean that a parent does not fully realise what a diagnosis means until some time has passed.

For example, the label 'global developmental delay' may be construed in different ways with a parent fully expecting a child to catch up with their milestones. A parent may be unaware that a particular diagnosis means their child will not live an independent life and it is not until a further milestone is missed, or a transition point reached (such as secondary school), that they fully realise the implications. A sense of loss can hit at these different points in their life and this may be expressed in appointments with professionals.

Other concepts such as Chronic Sorrow^{xl}, Dual Process Model^{xli} (Loss and Restoration), Continuing Bonds theory^{xlii} or Ambiguous Loss^{xliii} may be more relevant to some parents.

Roos defines chronic sorrow as 'a painful discrepancy between what is perceived as reality and what continues to be dreamed of. The loss is ongoing since the source of the loss continues to be present. The loss is a living loss.' (2002, p. 26).

The Dual Process Model is a model of coping with loss that allows for an oscillation between the 'commitment to positive action and the accommodation of loss'^{xliv}. In relation to parent carers it highlights the need for sensitivity to the individual response (at that time) and acknowledging the intense, even contradictory, emotions parents may experience.

Continuing Bonds contrasts with the usual model of griefwork, which involves a focus on 'moving on' from the loss, by allowing for a continuing relationship (albeit in a different form) with the loved one. Although this model was developed in relation to the death of a loved one this may be more closely aligned to some parent carers' journeys than the traditional 'grief stages'^{xlv} model.

Ambiguous Loss identifies the most severe life stressors as those that are not clear-cut and remain ambiguous. In such situations 'resolution of the situation is not possible and the outcome not predicable.'^{xlvi} O'Brien states that professionals who expect parent carers to go through the grief 'stages' fail to acknowledge the individual response and the lack of closure or resolution in cases of ambiguous loss.

Conversely, others do not identify with grief or loss which is powerfully expressed in the '#Wouldntchangeathing' campaign to challenge negative perceptions of Down Syndrome.

With this in mind, professionals need to avoid making assumptions about parental responses to their child's diagnosis and remain open to the individual's experience.

Trauma

Many parents will have experienced trauma: seeing their child go through invasive medical interventions, a difficult birth, behaviours that challenge or even day-to-day cumulative traumas and may show evidence of post-traumatic stress. It is important to recognise that, for parent carers, it may be small 't' traumas rather than big Traumas that are difficult to cope with. Feeling like you are battling on a daily basis – with your child, services or society can take its toll. Emerson (2019) says that 'UK services are not designed to support traumatized parents, and health practice may serve to compound distress'^{xlvii}.

Every experience of contact is potentially retraumatising and the quality of the interaction, requiring understanding and sensitivity, of utmost importance. One example of how to manage this is a family who 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.

Services can benefit from working in a trauma-informed way. Traumatized 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

It is important that the needs of the whole family are recognised and they 'receive the support that they want and need when they are ready (not what and when suits the system)'^{xlviii}. Further resources can be found in the references^{xlix} ¹.

Ongoing Process

Parent carer wellbeing is an ongoing process of adjustment rather than an endpoint that is reached and completed. One father described a phenomenon he termed 'issue fatigue' illustrating the 'perpetual stream of things to deal with' and little time to recover in between^{li}.

Furthermore, notions of positive or negative responses may be too simplistic as both can happen simultaneously: adaptation is not necessarily the 'absence of stress or other negative feelings'^{lii}. Emotional responses can vary day-to-day and professionals can help by framing these oscillating emotions as an understandable reaction to an unexpected situation.

'I needed someone to stop giving me the silver lining....I think just being given the space to talk about it, rather than anyone trying to minimise how you're feeling, is really helpful.'
– Parent Carer

5. What parent carers need: Combining practical and emotional support

Good support for families is possible. There are a number of factors families identify as important:

Compassionate, human relationships

Parents benefit from contact with services and professionals that are compassionate, trustworthy and understanding. They need to connect with family-centred (not just child-centred) services that offer good communication – listening as well as talking. Although at times parents need practical advice this always needs to be alongside a caring, empathic approach. This includes rapport with the child. A positive connection with a professional validates the parental experience and can help reduce isolation. It also creates a sense of working together as opposed to a 'them' and 'us' approach; this will also help in the future if there are tensions over support or services.

Holistic and co-ordinated

Services that fail to work together can add to the emotional load for parent carers and those that are proactive, rather than only reacting when a crisis occurs, will help prevent caregiver burnout. It is supportive when services can help coordinate appointments or chase up reports. The most holistic support may require practical and emotional support.

'I don't think anyone ever went in to social work thinking I'm going to make a massive difference by coordinating the departments to communicate together, but that is what I have

found to be the most beneficial part of having a named social worker, is actually just someone that can coordinate different departments.’ – Parent Carer

Further, ‘being able to see the same professionals and access the same services was a constant source of support’^{liii} and may result in reduced parental anxiety^{liv}. Ensuring that actions are followed, and referrals made, alleviates the parents from taking on the role of key worker as well as parent.

It is also useful to consider who else is advising the family as a multitude of advice and therapy programmes can be overwhelming. The expectations of a parent to be a combined occupational therapist, speech and language therapist and nurse is unrealistic, so targets need to be integrated in the families’ world. Failure to recognise the context for the family can lead to service input adding to stress levels rather than alleviating them.

Responsive, flexible and multi-faceted services

Services need to be responsive and flexible to the individual needs of the family. At times this might be empowering the parent to gain knowledge and find answers for themselves. Whereas at other times, particularly when stressors become too much, they may need services to help share the load. Therefore, the type of support needs to match the needs of the stressful event and the family’s resources, culture and background rather than offer a one-size-fits-all approach^{lv}.

[it is helpful to] ‘talk to other professionals who understand us as a family.’ – Parent Carer

Sometimes financial or practical support is necessary. Parents can be signposted to resources, benefits and groups as they are not always aware of available support such as Disability Living Allowance (DLA), Carer’s Allowance or Personal Independence Payments (PIP), respite opportunities or Short Breaks.

Empowerment and Collaboration

Supporting family carers to access good quality information and training enables them to be solution-focused and in control. Gaining knowledge and expertise can help counter feelings of helplessness. However, the quality and relevance of the training is key and generic parenting courses may not always address the very specific needs of the family and child.

Family carers (mothers *and* fathers) are experts by experience on their child and should therefore be routinely invited to work in partnership with professionals. Parent carers wish to be consulted, and communicated with, to ensure they have the information they need. For example, a home-school book so parents know what has happened during the day.

‘what helps is when services work with me [and] when I have really good communication with people that are supporting my daughter.’ – Parent Carer

Valuing the role carers play and building on their strengths can help improve well-being of the whole family. For example, referring to ‘Mum’ in meetings rather than the person’s name can be interpreted as a lack of value in the parental viewpoint. As Ryan and Runswick-Cole state:

‘mothers can extend their caring role to broader community or social concerns [however, they] are often in an ambiguous position of having no recognition or credibility in professional circles [which] highlights how little value generally is placed upon the skills, expertise and resources that mothers of disabled children accumulate and, again, underlines their liminal position.’^{lvi}

Professionals can empower parents by affirming their concerns and confirming that they are 'engaging in helpful strategies or practices to support their children'^{lvii}. Often parents want to know that they are doing a good job.

There is also an important role for professionals in helping affect social change by campaigning for better services or changes in society; working alongside parents to elicit great inclusion and accessibility. For example, telling a parent that there are no available Occupational Therapists at the moment, shouldn't be the end of the conversation. What is being done about it? To whom do we raise our concerns? Parents can be a powerful advocate and may help you in your work.

Sharing the load

As well as chances to empower parents there may be times when the family need extra support. It is important this is not viewed as a deficiency or failure on the part of the family; rather there is a recognition of competing demands and limited resources.

'I was having problems with her equipment, so they said just bring her down and while she was there they contacted wheelchair services, got that sorted out, like they stepped in. They took over. They took the problem, they tried to sort that out and the wheelchair was ready by the time she come back again, they put a blanket around you.' – Parent Carer

There may be times when families need empowering to manage on their own and other times when they need some extra support in sharing the load. Resilience is a dynamic, rather than static, process.

Time for themselves

All carers need time away from their caring duties and parent carers are no exception. It is a basic human need that we have time to engage in activities that are meaningful and important in our lives. This is not an added luxury that carers should feel guilty about; it is a key aspect of the caring role.

Professionals can help assuage some of the guilt that parents often report feeling, by framing time off as necessary in order to avoid caregiver burnout. It will involve finding appropriate care cover and signposting parents to appropriate service provision.

6. Emotional support – helping professionals to help parent carers

Recognising the emotional impact on parent carers includes having a basic understanding of how emotions affect people's wellbeing and behaviour.

'we do get a lot of support with her diet and blood tests, but it's all the medical side, it's not actually how are you feeling about this, how are you dealing with this diagnosis?'
– Parent Carer

Understanding distress

Someone who is under significant stress is more likely to react (that is instinctively) rather than being able to think and reflect before responding to things in their environment. When carers are overwhelmed or exhausted, seemingly harmless comments can be taken as criticism or judgement. Professional sensitivity and awareness of the emotional state of the family carer can ensure best outcomes for the whole family. It can help to imagine how you would feel if a loved one was in the same situation.

It is human nature that we tend to get 'in sync' with the emotional states of others around us. This means that some interactions may lead professionals to feel defensive. Being aware of this possibility may help us catch ourselves and try to remain open and socially engaged. Rather than meet the responses of families with defence it can help to try to understand where the parent is coming from. This involves an emotional understanding that can help all aspects of your practice. Attending training on showing empathy and effective communication skills can help minimise the potential for miscommunication and enable you to offer the appropriate support for a family in distress.

With this in mind it may be useful to think of stages of support.

A chance to talk

In the first instance it may be helpful to listen to the person's concern with compassion and openness. Parents may be very knowledgeable and competent, which may mask potential vulnerabilities. Sometimes parents are reluctant to talk about their own feelings or any personal struggles, due to shame or embarrassment^{lviii}. It may be useful if you start the conversation with open questions and sensitivity to whether this is something they wish to talk about; being respectful of peoples' rights not to open up if they do not feel ready to.

There may not always be a solution to the problem but the act of sharing their experiences, with someone who is understanding, may alleviate some concerns. By acknowledging emotions it can help parents to identify and cope with them, rather than feeling like they are 'unsayable'.

'it's just getting it out there and just saying, these are all the things that are happening, because what I generally find is...you can almost talk yourself into a solution when you're talking' – Parent Carer

These can be difficult conversations yet if handled skilfully they can be an important support for the parent's emotional wellbeing and thereby the whole family. It may mean a referral onto other services is not always necessary.

Group support

Parent carers often report feeling isolated and meeting other family carers can help build a sense of community. This may include attending group and social activities outside their caring role. Being part of a group that is supportive and becomes integrated as part of our identity has massive benefits for mental health. As we gain a sense of being part of a group it further helps us connect with others and can provide what is often referred to as a 'social cure'.

By connecting with the special needs or disability community – be it face to face or online – parents can strengthen their wellbeing and coping capacity even in adverse situations, such as 'being the target of discrimination and prejudice'.^{lix}

Sometimes parents who struggle with their old friends, or wider family, may instead find a new special needs parent network. If a family you are supporting finds it hard to join a new group this may be an important role for a professional to take on, providing a 'social scaffold'^{lix} to help access it.

Practical support

At other times supporting the parent to access practical support will benefit their wellbeing, such as short breaks or the appropriate educational interventions.

Further emotional support

Sometimes parents benefit from accessing more specialist emotional support; there are several issues to consider.

A generalised emotional support service may not always be the most appropriate for all parent carers. It is a personal choice whether a parent wants a protocol based counselling service, such as Improving Access to Psychological Therapies (IAPT) or a more bespoke service that understands the context in which parent carers find themselves. Services that can offer flexibility in their appointment systems, or offer online sessions, may help those who find it hard to leave the house or arrange appropriate childcare for their child.

'I don't think CAMHS is set up for our kind of situation because we needed the input irregularly, unpredictably around hospital admissions.' – Parent Carer

There are different counselling or psychological approaches which offer the chance to develop emotional understanding and learn new coping strategies, such as mindfulness^{lxi}, acceptance and commitment therapy techniques^{lxii} or other psychological therapies. An integrative stance is helpful to acknowledge that parents may need different support at different times.

Finding a local service with relevant expertise can depend on your location. There is a list of services identified at www.affinityhub.uk which is regularly updated.

Your own emotional needs as a professional

Utilising your own emotional intelligence, emotional regulation and skills such as active listening may help to create a connection with a parent. Rather than a hierarchy, parents welcome an equitable relationship including a professional acknowledging when they do not always have the answer. This can help create a sense that both professional and parent are in this together.

'our local consultant...is brilliant, I mean she would say, [our daughter] is very complicated, and its been a learning curve...for all of us' – Parent Carer

There may be times when supporting parent carers feels professionally overwhelming. Parent carers have often become knowledgeable and well versed in their child's needs. This may lead some professionals to wonder what they can add and to question their own expertise. Working alongside families and learning with them and from them can help.

As mentioned above, it is important to be mindful of our own emotional and physiological states. At times it may be upsetting or even traumatising to be in contact with families in distress. Ensuring that your own supervision, peer support and continuing professional development requirements are in place will enable you to better support the families with whom you work.

Sometimes the nature of the institution in which you work may make it harder to emotionally support parents. The recognition of self-care as an important part of your role needs to be embedded in the structure of the system. That means that the individualised quality of care is just as important as the quantity of care and can have longer term benefits.

Conclusion

By understanding the emotional landscape for parents, services and professionals can provide better help: acknowledging the difficulties, communicating in an open and trustworthy way and working in collaboration to support meaningful outcomes.

Professionals can offer a safe space to talk through their feelings which may help parent carers to see things from a different perspective as well as developing greater coping skills. This in turn can foster positive and empowering relationships that benefit the whole family system. At times, though, parent carers may require additional support for their emotional wellbeing.

The first author has established a Parent Carer Wellbeing Network for professionals working with this community to share good practice and networking opportunities. If you would like to register please email jo@griffinpsychology.co.uk

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***What does Special Educational Needs and Disabilities (SEND) and Additional Learning Needs (ALN) mean?**

A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support (SEND). We have also used the term 'disabled child' as it is common nomenclature and recognise that people have preferences for different terminology.

For the purposes of the document we are referring to children with the following:

Asperger's syndrome, autism, autism spectrum conditions, developmental disability, global developmental delay, learning disability, intellectual disability, neurodevelopmental conditions and neurodiversity, special educational needs, additional learning needs.

Who this guidance is for:

This guidance is for all professionals who come into contact with parent carers including: family support workers, general practitioners, health visitors, occupational therapists, paediatricians, physiotherapists, social workers, speech and language therapists, teaching staff, transition workers and other health, education and social care professionals.

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Glossary

Annual Reviews

By law, Education, Health and Care plans (EHCPs) should be reviewed at least once every year, in a formal meeting known as an annual review.

Carer's allowance

A Government allowance if you if you care for someone at least 35 hours a week and they get certain benefits.

Carer's Assessment

An assessment undertaken by, or on behalf, of social services to assess what support you may need if you care for someone.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS are the NHS services that assess and treat young people with emotional, behavioural or mental health difficulties.

Children and Families' Act 2014

The Children and Families Act 2014 covers adoption and contact, family justice, children and young people with Special Educational Needs (SEN), childcare and child welfare. It introduced EHCPs.

Crisis Mental Health Teams

Crisis resolution and home treatment (CRHT) teams can support you if you have a mental health crisis outside of hospital. They're often called crisis teams for short, although you might find your local service is called something different.

Disability

You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities. <https://www.gov.uk/definition-of-disability-under-equality-act-2010>

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a benefit for disabled people. It's a monthly, tax-free payment. It's gradually being replaced by Personal Independence Payment.

Education Health and Care Plans (EHCPs)

An education, health and care (EHC) plan is for children and young people aged up to 25 who need more support than is available from within an education setting's own resources. EHC plans are a legal document which identify educational, health and social needs and set out the additional support to meet those needs.

Local Authority

An administrative body in local government.

Multi-disciplinary team (MDT)

A Multidisciplinary Team is a group of professionals from one or more clinical disciplines (e.g. paediatrician, psychologist, physiotherapist, occupational therapists, speech and language therapist) who together make decisions regarding recommended treatment of individual patients.

Occupational Therapist

Occupational therapy provides practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them.

Pathologised

Regarded or treated as a disease or psychologically abnormal or extreme.

Personal Independence Payment (PIP)

PIP is for people between 16 and 64 who need help at home because of an illness or disability.

Physiotherapist

Physiotherapists help people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice.

Psychologist

Psychology is the scientific study of the mind and how it dictates and influences our behaviour, from communication and memory to thought and emotion. It's about understanding what makes people tick and how this understanding can help us address many of the problems and issues in society today.

Respite

Respite care means taking a break from caring, while the person you care for is looked after by someone else.

Short breaks

The term 'short breaks' is used to describe the time off that family carers and disabled people receive. These breaks come in different forms. Some families access short breaks at centres, others are part of schemes involving placements with families. Some receive direct payments to buy their own support.

Social Model of disability

The social model of disability was developed by disabled people in response to the previous medical model, which focused on diagnosis and difference as the main cause of disability.^{lxiii}

Social services

Social care is the provision of social work, personal care, protection or social support services to children or adults in need or at risk, or adults with needs arising from illness, disability, old age or poverty.

Special Educational Needs and Disabilities (SEND)

A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support (SEND). The SEND Code of Practice 2014 and the Children and Families Act 2014 gives guidance to health and social care, education and local authorities to make sure that children and young people with SEND are properly supported.

Speech and Language Therapist (SLT)

Speech and language therapists provide treatment, support and care for children and adults who have difficulties with communication, or with eating, drinking and swallowing.

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