June
2025

SHORT BREAKS, JIGSAW AND SOCIAL CARE – FAMILIES EXPERIENCES

Influencing Positive Changes

Southampton Parent Carer Forum CIC

EXECUTIVE SUMMARY

This report highlights significant concerns and challenges faced by families of children and young people with SEND in Southampton, particularly relating to social care, short breaks, assessments, and service provision. Despite legislative frameworks designed to safeguard and support these families—such as the Chronically Sick and Disabled Persons Act 1970, Children Act 1989, and Equality Act 2010—there remain systemic barriers and inconsistencies in service delivery.

Key issues include lack of transparency and fairness in policies and their application, limited and inequitable access to short breaks and play schemes, delayed or insufficient assessments (especially for children with learning disabilities and neurodivergence), and inadequate support for young carers. The absence of a coherent, needs-led approach to assessment often results in families being passed between services or left without appropriate support.

Families also report difficulties engaging with the complaints and appeals processes due to inconsistent handling, lack of timely responses, and a perceived imbalance that favors professionals over families. Communication gaps, such as insufficient consultation on policy changes and lack of accessible engagement opportunities, further undermine trust.

Transport barriers, the reduction of specialist provision in the community, and suggestions by professionals that undermine educational attendance exacerbate family stress and reduce quality of life. The system frequently fails to adequately recognize the complex, holistic needs of families, particularly those with neurodivergent children or multiple SEND within the household.

This report underscores the urgent need for co-produced, transparent, and equitable services that uphold families' rights, promote the welfare of disabled children and their siblings, and provide meaningful respite and support to sustain family wellbeing.

WORKING RELATIONSHIP

When Social Care first began working with the Parent Carer Forum back in September, there was a real sense of hope and optimism. We believed this marked the beginning of a genuine partnership. One where we could work together with the Jigsaw team to create a fairer, more transparent, and more equitable service for families of children and young people with additional needs.

However, as time has gone on, many families feel that this promise of change has not yet materialised. Despite early conversations, the experiences families continue to report suggest that the system is still not meeting their needs in a consistent or compassionate way. This has led to growing frustration, a loss of trust, and in some cases, a deep sense of being unheard or unsupported by the very services designed to help them.

We now see this moment as a critical turning point and an opportunity to pause, reflect, and commit to meaningful change. This should not be about blame, but about building a better future together. We believe it’s time to bring everything to the table including the concerns, the barriers, the lived experiences and work openly and constructively to co-produce a clear, practical plan for moving forward.

This is a chance for a fresh start and one that puts families at the heart of decision-making and ensures that support is designed with, not just for, those who rely on it. With true co-production, transparency, and a shared commitment to improvement, we can rebuild trust and create a system that works for all families, not just some.

Let’s use this moment not as a setback, but as a positive step forward one rooted in partnership, accountability, and hope.

WHAT IS CO-PRODUCTION?

The SEND Code of Practice: 0 to 25 years (January 2015) does not always use the word “co-production” explicitly in every instance but makes it very clear that Parent Carer Forums (PCFs) and parent carers must be involved in the development and review of local policies, services, and decisions, which includes co-production.

Here are the key sections where this principle is outlined:

Chapter 2: Implications of the Code of Practice
2.1: "Local authorities must have regard to the views, wishes and feelings of the child or young person, and the child’s parents... and must enable them to participate in decisions."
2.4: "Local authorities must work with children, young people, and parents to review and plan the local offer."
This indicates that any policies forming part of the Local Offer must be co-produced with families and PCFs.

Chapter 4: The Local Offer
4.7: *"Local authorities must involve children and young people with SEN and disabilities and the parents of children with SEN in:

- planning the content of the Local Offer
- deciding how to publish the Local Offer
- reviewing the Local Offer and deciding how to revise it"*

4.8: "Local authorities should engage with Parent Carer Forums..."
Although the term “co-production” isn’t used here, active involvement in planning, reviewing, and decision-making is co-production in practice.

Chapter 3: Working Together Across Education, Health and Care
3.64: "Local authorities should ensure that children, young people and parents are involved in the strategic commissioning of services. This is an important aspect of the Local Offer and of the joint commissioning arrangements..."

What Counts as “Co-production” in the Code?
Although the Code doesn’t define "co-production" in detail, the Department for Education and Contact (previously Contact a Family) have clarified that when the Code says:

- “involve”
- “participate”
- “work with”
- “engage with Parent Carer Forums”

— these all point to co-production as defined in SEND reforms (equal and reciprocal partnership from the start).

This applies to policies at a strategic level and again implies co-production, particularly with PCFs who represent families in this strategic context. But the duty to involve families and PCFs in planning, reviewing, and decision-making is clearly stated in multiple places, especially in Chapters 3 and 4. That requires co-production under the SEND reforms.

HOW WE WORK AS A PCF?

At Southampton Parent Carer Forum, we have a clear structure and a consistent approach to how we work. A director or steering group member usually represents the forum at meetings, where we bring the voice of families across the city. This takes place through a variety of strategic groups and partnerships.

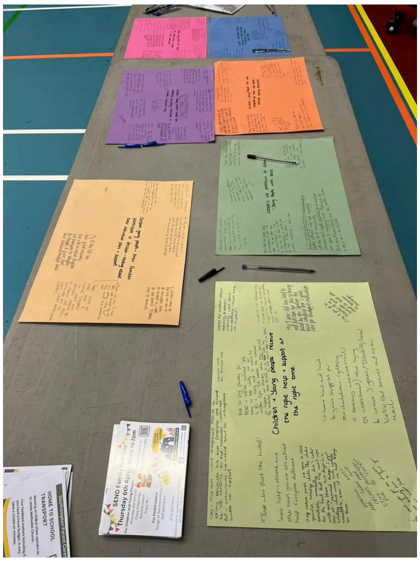
The directors and steering group members have had specific training to do this to represent the voice of the city along with giving examples from their lived experiences or other families lived experiences. We are here to advocate for families in the city and not to advocate for individuals.

We make sure that the information we gather is shared with families in accessible and inclusive ways, recognising the diversity of our local community. This includes updates through social media (including a private group), regular newsletters, informal coffee meetups, and by working alongside professionals

We also support consultation events to ensure that all families have the opportunity to be heard. Our work is funded by the Department for Education, Southampton City Council, and the Integrated Care Board (ICB), and we remain independent as a Community Interest Company (CIC).

When Ofsted and the CQC carry out inspections, we are contacted directly and play an active role in those processes, helping to make sure the voices of parent carers are central.

As you read the rest of this report it is important to keep the below in mind and how we deliver this as a local authority. As this remians some of the current guidance.



Feedback collected at Infltazone Feb 2023

The below quote is from the Disabled Children’s Social Care: Consultation Paper 265

‘Section 2 of the Chronically Sick and Disabled Persons Act 1970 is focused exclusively on disabled children. The services that can be provided as a result of section 2 are more limited and consist of:

1. providing practical assistance for the child in their home;
2. providing “wireless, television, library or similar recreational facilities” for the child, or assisting them to obtain them;
3. providing lectures, games, outings or other recreational facilities outside the home;
4. assisting the child to take advantage of educational facilities;
5. putting in place and/or helping with travel arrangements, so that the child can participate in the services that have been arranged for them;
6. providing assistance in arranging adaptations to the home;
7. providing facilities to secure greater safety, comfort or convenience for the child;
8. facilitating the taking of holidays by the child;
9. providing meals for the child; and
10. providing a telephone for the child, or special equipment necessary for the child to use one.

9.4 Technically, these services are not provided under section 2 itself. The services are provided under Part 3 of the Children Act 1989, and most typically section 17.[426] But the effect of section 2 of the Chronically Sick and Disabled Persons Act 1970 is to require local authorities to provide these specific services – which would otherwise be discretionary – in circumstances where the local authority judges it to be necessary in order to meet the needs of a disabled child.’

SHORT BREAK STATEMENT

The previous short break statement was created in full co-production with the Parent Carer Forum, supported by a series of public consultation events to ensure a wide range of parent voices were included. This approach helped to build trust, increase transparency, and ensure the final document truly reflected the lived experiences of local families. However, while there was one brief meeting toward the end of last year to begin reviewing the updated short break statement, no further updates or opportunities for input have been shared since until the recent meeting on 18th June, when we were informed the document is now undergoing final checks before being published for comment on the Local Offer soon.

This lack of engagement is deeply concerning. As a Parent Carer Forum, we have not been given the chance to comment on the updated statement and something that has always been seen as a key part of effective co-production. Families of children with SEND often rely on short breaks to prevent crisis, maintain employment, and sustain their own health and wellbeing. These families need to be included in every stage of developing and reviewing such vital information. Furthermore, many families do not regularly access the Local Offer website and will be unaware that there is an opportunity to comment unless other methods of communication are used. Digital-only feedback methods risk excluding families with limited internet access, language barriers, or additional caring responsibilities. Families have told us they would value face-to-face opportunities, through drop-ins or information events, where they can ask questions and give meaningful feedback. We are also unclear whether all families currently accessing short breaks will be proactively notified of the updated statement and this was not clarified at the recent meeting. Without accessible and inclusive engagement, the result risks being a statement that does not reflect real family need.

NEW POLICY

Over recent months, we have been contacted by a growing number of families reporting that a "new policy" is being applied to their child’s short break support. However, when families request a copy of this policy, in order to understand the changes being made, social care staff have often been unable to provide it, or have told parents it is "not available." This leaves families feeling confused, anxious, and powerless, particularly when their child’s package has been significantly reduced or changed without explanation. For families already juggling medical appointments, care needs, and educational challenges, this lack of transparency adds unnecessary distress.

The absence of a clear, published policy also raises serious concerns about equality and fairness. If some families are being told one thing while others are told another, and there is no written guidance available to ensure consistency, then there is a real risk that decisions are being made without accountability. Families are already under significant strain; they deserve to understand the processes and criteria used to determine the support their children receive. The SEND Code of Practice is clear that support should be developed in partnership with families, not applied behind closed doors. Without clear communication and accessible information, families cannot advocate effectively — and trust between parents and professionals breaks down.

DIRECT PAYMENT POLICY

At the meeting held on 18th June, it was stated that a new Direct Payment Policy had been written and would shortly be published on the Local Offer. As of 1st July, this policy still does not appear to have been shared publicly despite the fact that the new Resource Allocation System (RAS) linked to direct payments has already been in use for more than six months. This raises serious concerns for families, especially those whose budgets have been cut or whose packages have changed without explanation. To have a new approach in place without a published policy, or a consultation process, completely undermines principles of transparency, fairness, and co-production.

The SEND Code of Practice is clear that families should be actively involved in shaping the support and policies that affect their lives. Not only has there been no opportunity for parents to help shape the new policy, but families have told us they were not even made aware that a new framework for allocating direct payments had been introduced. This leaves parents feeling unheard and devalued. Many families depend on direct payments to fund trusted support workers, personal assistants, or accessible leisure activities. Sudden changes without a clear explanation or the chance to influence decisions have a real-world impact: children losing relationships with familiar carers, parents unable to balance work and caring roles, and a growing sense of instability and frustration. We urge the local authority to pause the finalisation of this policy until genuine co-production has taken place and families' voices are at the heart of the process with the PCF.

CASE BY CASE COMMENTS

In meetings, we frequently hear phrases such as “on a case-by-case basis” or “subject to discussion with a manager” when it becomes clear that a published policy may not be followed. While flexibility can be important, repeated reliance on these phrases often indicates that the policy lacks clarity, consistency, and transparency. For families, this creates uncertainty and raises concerns about fairness and equity. When policies are not applied consistently, it can lead to inconsistent decision-making, with outcomes depending more on individual interpretation than on a clear, shared framework. This undermines trust and makes it difficult for families to understand their rights or know what to expect.

APPEALS

A statement was recently published via the Local Offer social media page suggesting that the appeals process for short breaks and personal budgets had been consulted on with families. However, this is not an accurate reflection of what actually took place. At a routine coffee morning which was marketed as a general Q&A session by the PCF and not a formal consultation. A small number of attendees were briefly shown a draft version of the appeals process. A few of them took copies away, but no structured consultation process was followed. Importantly, some of those present were not current users of the Jigsaw service and therefore not directly affected by the policy. If a formal consultation was intended, this should have been clearly communicated in advance, giving the Parent Carer Forum an opportunity to support wider engagement, promote the event appropriately, and ensure the voices of families most affected were fully represented.

This lack of clarity and true engagement is especially concerning because the appeals process has significant real-world implications for families. We are hearing from families that there is no consistency in how appeals are handled. Some parents report that while they are going through the complaints or appeals process, their child’s original personal budget continues, allowing vital care arrangements to remain in place. Others, however, have had their packages immediately stopped, causing disruption to their child’s care, termination of trusted support arrangements, and intense stress on the family unit with reimbursement only happening once a decision is reached, which can take weeks or months. This inconsistent approach creates a two-tier system, where the outcome depends more on who you speak to than the strength of your child’s needs.

Furthermore, we are increasingly concerned about how the appeals process disproportionately affects families who face barriers to communication, advocacy, or understanding of the system. Families who are articulate, confident in written communication, and familiar with the processes often do well during appeals. In contrast, those who experience poor literacy, mental health challenges, language barriers, or a limited understanding of their rights often struggle to present their case effectively. These families may find the process overwhelming, unclear, or emotionally distressing and may abandon their appeals entirely, simply because they don’t feel heard or supported. The result is an appeals process that does not feel fair or accessible for all families, and risks deepening inequalities in access to essential support.

To ensure genuine equity, the appeals system must be designed and communicated in a way that is transparent, inclusive, and co-produced with those who will be using it. Families need clear information, consistent handling, and support to navigate what is often a very complex and emotionally charged process. We urge the local authority to revisit both the consultation and the appeals procedure itself in genuine partnership with the Parent Carer Forum and with a clear plan to include the voices of those who are most often left out.

MAX CARD

The Max Card is still being promoted however, its of little value locally and does not really provide a low to medium tier provision as it was originally intended. Within the city it can only be used at

1. Monkey Buziness to allow one adult in for free(however other cards are accepted as well and they do not offer quieter SEN sessions so its not accessible to some young people)
2. Board in the city
3. Sea City museum (Free Carer)
4. Tudor House (Free Carer)

This meets the needs of a very limited group of children under the current medium tier of support.

At the coffee morning in February the Jigsaw staff agreed they would reach out to other venues in the city to see of they could increase the range of places which support the Max Card however we are yet to see any additional services/provisions added to the list in the city.

At that same coffee morning, Jigsaw staff mentioned they would make efforts to encourage other local businesses to offer SEND sessions with smaller group sizes. This would create a quieter, less crowded environment, making activities more accessible and comfortable for young people with neurodivergence or similar needs who find busy venues overwhelming.

OVERNIGHTS AND PLAYSCHEMES

The overnight short breaks service, delivered by Rose Road, currently runs from 4pm on one day to 3pm the following day effectively providing both an overnight stay and a full day of care. While this structure is welcomed by some families who find it extremely beneficial, others have raised concerns about inequality in access and fairness.

Some families feel that this model provides what is essentially a double benefit: both an overnight respite and the equivalent of a playscheme day. This has led to situations where a small number of families are able to book a playscheme day followed by two consecutive overnights, gaining up to three full days of respite. While this can be life-changing support for those who receive it, other families particularly those who are not allocated overnights feel this is unfair and creates an imbalance in how respite is shared across the system.

For those without access to overnight provision, the feeling is that one overnight equals 23 hours of care, significantly more than a standard day of playscheme, yet it is not always counted or managed differently in the overall allocation process. This perceived lack of consistency causes frustration and distress, especially for families who are already struggling to cope without adequate breaks.

Additionally, because overnight stays extend well into the following day, they can reduce the availability of daytime spaces at the setting. This limits access for other families seeking daytime respite, particularly during school holidays, and contributes to a sense of exclusion and inequity within the system.

The impact on families is significant. Those who receive fewer hours or no overnight provision often report feeling forgotten, unsupported, and overwhelmed, while those receiving more support can feel judged by others. This creates tension within the parent carer community, when in reality all families are trying to access the support they need to survive and care for their children. There is a growing call for a more transparent, equitable and needs-led approach to how respite hours both day and night are allocated and managed.

COST OF PLAY SCHEME

Families have been informed under the new policy which is being applied already that they can not use direct payments for play scheme as it is inline with the costs of a non SEN specialist provision. However, this does not appear to be the case. Please see the costs and times on the next page.

Provision	Times	Cost for session	Cost per hour
Rose Road	10 to 3	£29	£5.80
Mencap	9.30 to 4	£19.25	£2.96
Testlands Holiday club	9 to 3 8 to 6	£22 £33	£3.66 £3.30
RISA Sports (Southampton	10 to 3	£12	£2.40
Super Star Sports	9 to 3	£20	£3.33
Highfield Multisport	8.45 to 3.15	£18	£3.00
Shirley Junior School	9 to 3	£20	£3.33

Test lands and Superstar sports are the two biggest holiday club providers in the city. RISA advertise they are SEN friendly and are quite new so limited feedback. A couple schools have been included too for balance.

Families can also use the government tax free childcare scheme to get 20% off. As far as we are aware this is not available at Rose Road increasing the difference in costs. This is having an impact on families especially those who are already struggling financially or just making ends meet.

This shows that parents of disabled children are being charged more if they opt for Rose Road and this would go against the Equality Act 2010, section 20 and 21 as there are no reasonable adjustments in place to bring the cost inline with other providers. It could also be seen as direct discrimination to charge disabled children more because of their disabilities. Previously families could use their short break funding which would be considered a reasonable adjustment and mitigate against this.

The Children Act 1989 (Section 17) places a duty on local authorities to provide services to disabled children to reduce the impact of their disability. That includes not creating additional financial barriers.

In addition, families consistently report that Rose Road’s playscheme allocation process is unclear and often delayed. Contact is frequently made very late in the run-up to school holidays, leaving parents stressed and anxious as they try to make care arrangements around work, other children, or additional appointments. When asked what days they need, families often say that if they request three days, they receive only two — and if they ask for two, they are given just one. This has created a sense of unfairness and concern where families feel they need to over-request in order to get what they actually need. Those who are new to the system are often caught out and left with insufficient support, while more experienced families feel forced to play a guessing game in order to secure vital respite.

Another growing concern is that Rose Road is only open for young people to attend on 15 working days out of the 29 working days during the summer holiday, significantly limiting availability — particularly during longer school holidays when the need for support increases. This restricted access is especially difficult for families who have no other care options, as well as for those whose children need consistent structure and routine to feel safe and regulated. For many children with SEND, especially those with complex needs, a sudden change in schedule or reduced access to a familiar setting can cause distress, anxiety, and behavioural regression. Parents are then left to manage intense care needs without support, often while juggling work or health issues of their own. With demand far outweighing the number of available places, this system leaves families exhausted, unsupported, and at breaking point, and leaves children missing out on safe, social, enriching experiences they are entitled to.

We urge that the playscheme allocation process be made more transparent, timely, and needs-led, with improved communication and a review of provision to better meet the growing demand in the city.

TRANSPORT TO SHORT BREAKS

The Chronically Sick and Disabled Persons Act 1970 (CSDPA), Section 2 requires local authorities to arrange practical assistance, including:
'assistance in travelling to and from home for the purpose of participating in any services provided under this section.'

Within the Children Act 1989 – Section 17 places a general duty on local authorities to safeguard and promote the welfare of children in need — including disabled children — by providing services to meet their assessed needs.

- Transport to access a short break could be part of a Child in Need (CIN) Plan.
- If a social care assessment finds the short break is necessary for the child or family's wellbeing, transport can be included as part of the support package.

While the SEND Code of practice (2015) is guidance rather than law, it is statutory and must be followed. It says:
Paragraph 4.44: The Local Offer should include information about:

- How services are accessed, including any criteria for access (e.g., transport for short breaks).

So the Local Offer must be transparent about whether and how transport is provided to short break providers.

We believe there is work to be done around this and it should be on the local offer for all to see in a clear and transparent way.

Another significant concern raised by families is the lack of transport provision to playschemes, which is placing a growing burden on parents and carers. Many are having to use their own vehicles or rely on public transport to get their children to and from settings — often located across the city. For those living on the opposite side of Southampton from the playscheme venue, each round trip can take between 90 minutes to two hours, depending on traffic and accessibility needs. As a result, what is advertised as a 5-hour short break can be reduced to just 2.5 to 3 hours of actual respite time once travel is factored in.

This has a real and lasting impact on families. The original intent of short breaks is to provide parents with meaningful time to rest, manage work, care for other siblings, or attend to their own health and wellbeing. When a large portion of that time is spent on the road, the value of the break is significantly diminished. For some, the stress of transport logistics negates the benefit of the break altogether.

In addition to the time lost, families are also facing increasing financial strain. Rising fuel costs, and time to manage these journeys all contribute to hidden costs that many families of children with SEND simply cannot absorb. For those without access to a car, public transport can be unreliable, time-consuming, and inaccessible particularly for children with mobility needs, sensory sensitivities, or high anxiety.

The lack of a funded or supported transport offer creates a barrier to access and results in unequal opportunities for children with SEND, especially those from lower-income households or marginalised communities. It also undermines the core purpose of short breaks which is to support family resilience and reduce pressure on the care system.

We urge that transport needs be fully considered as part of any short breaks strategy, to ensure that access to provision is fair, transparent, and genuinely supportive of families across the city.

HAF AS A ALTERNATIVE

Members of the Jigsaw social care team frequently signpost families to the Holiday Activities and Food (HAF) programme. While this scheme can be helpful for some, it it can be unsuitable for families with disabled or neurodivergent children. HAF has significant limitations on the types of needs it can support, and the availability of specialist SEN provision is extremely limited across the city with just up to 12 places available at 3 locations, covering only 4 out of the 6 summer holiday weeks. For a city the size of Southampton, this falls far short of meeting demand.

Families are also restricted to a set number of tokens, meaning even when places are available, access is capped. Most HAF activities have an upper age limit of 14, which excludes older young people with SEND who may still require significant supervision and support. In some cases, parents or a 1:1 carer must accompany their child, which removes any opportunity for respite, a key need for many families navigating complex care responsibilities.

HAF is also not available during October, February, or May half terms, leaving further gaps in support throughout the year.

Additionally, HAF bookings go live before other services, such as Rose Road, have confirmed their own summer provision. This leaves families in a difficult position, forced to choose between waiting for the service that best meets their child's needs, or risking missing out on HAF altogether when places fill quickly. As a result, many families find themselves with little or no support over school holidays, contributing to increased stress, isolation, and burnout.

The HAF programme is not a reliable or sustainable offer for families of children with SEND, as it is entirely dependent on time-limited government funding, which is subject to change frequently. This means there is no long-term guarantee that the scheme will continue, or that the level of provision and support will remain consistent. For families who rely on this support to manage childcare during school holidays, plan around employment, or provide meaningful social opportunities for their child, this uncertainty creates significant anxiety.

Additionally, the lack of guaranteed continuity makes it extremely difficult for families to plan ahead, particularly those whose children need routine, predictability, and consistent support workers. The risk of HAF funding being reduced or removed leaves families vulnerable to being left without any alternative provision, especially if other short break options are already oversubscribed or not suitable. For children with more complex needs, the sudden loss of a familiar, structured setting can result in emotional distress and disruption to progress made in confidence and social development.

In short, while HAF can provide some temporary benefit, it is not a reliable or equitable replacement for a fully funded, long-term short breaks strategy that meets the diverse and ongoing needs of children with SEND and their families.

SOUTHAMPTON
HAF
Holiday Activities & Food

CHILDREN AND YOUNG PEOPLE WHO REQUIRE 2:1

The current system is not set up in a fair or equitable way for children and young people who have been assessed and have it clearly documented in their Education, Health and Care Plan (EHCP) as requiring 2:1 support in the community. Under the existing direct payment and Resource Allocation System (RAS), each child is awarded a set number of points based on their assessed needs, which then translates into a fixed budget. However, this system does not take into account the increased cost of delivering care to children who require two personal assistants (PAs) at all times for safety, medical, or behavioural reasons.

As a result, when families use their direct payments to employ two PAs as is necessary for 2:1 support the available hours of support are instantly cut in half. For example, a family who receives enough funding for 5 hours of support per week based on the RAS score can only access 2.5 hours if 2 PAs are needed, because they must be paid simultaneously. Meanwhile, a child with the same RAS score who only needs 1:1 support receives the full 5 hours — double the time, despite having the same assessed level of need.

This creates a deeply unfair situation in which the children with the highest and most complex needs end up with the least access to community activities and respite, purely due to the way funding is calculated not their actual entitlement or level of support required. Families describe feeling penalised for their child’s level of need, with many unable to stretch their budgets far enough to provide meaningful, consistent support. This often results in children missing out on vital social opportunities, access to the community, and experiences that promote independence, communication, and wellbeing.

Moreover, this places additional pressure on parents and carers, who must fill the gaps in provision themselves, often at the expense of their own mental health, employment, and family balance. It also creates a two-tier system, where only families with the means to top up care out of their own pocket can secure appropriate support.

We urge that the direct payment policy and RAS be reviewed to recognise and accommodate the cost implications of 2:1 support, so that children with complex needs are not unintentionally disadvantaged by a system that is supposed to be person-centred and needs-led.

JIGSAW CRITERIA FOR SUPPORT

Families frequently report significant challenges in accessing assessments through the Jigsaw service and the CRS (Children's Referral Service) front door. One of the main issues is the lack of clarity around eligibility criteria and what constitutes a diagnosable condition versus a needs-led approach. This means that families often face confusion and frustration when trying to understand whether their child qualifies for support, with many feeling that access is being determined more by labels or diagnosis rather than the actual needs of the child and family.

In particular, children with learning disabilities (LD), especially in the early years, are often not adequately assessed or identified. Early identification and assessment are crucial for timely intervention, but many families experience delays or find that their child's needs are overlooked if a formal diagnosis hasn't been made yet. This delay can result in lost opportunities for support that would improve the child's development and reduce family stress.

Moreover, the current system appears to prioritise diagnosis over a holistic, needs-led assessment approach. Families report that unless a child has a formal diagnosis, their access to services is limited, even when their functional needs are evident and significant. This approach fails to recognise the complexity of neurodivergent children and those with emerging or complex needs that don't neatly fit diagnostic categories.

The front door processes, including referrals through CRS and Jigsaw, often lack transparency, leaving families uncertain about what to expect, how long assessments will take, and what criteria are being used to make decisions. This uncertainty exacerbates parental anxiety and can lead to families feeling unsupported and isolated.

Overall, the system's current assessment pathways create barriers rather than support, particularly for those children who are in the early stages of needing support or whose needs are complex and don't fit conventional diagnostic boxes. Without clear, needs-led criteria and timely assessments, families are left struggling to access the vital support their children require to thrive.

NEURODIVERSITY

Children with neurodivergent conditions are legally recognised as disabled under the Equality Act 2010 if their condition substantially affects their daily life over the long term. This legal recognition entitles them to protection against discrimination and access to support and accommodations across education, social care, and other services.

As a Forum, we are increasingly hearing from families that there are concerns regarding the Jigsaw service's understanding of neurodiversity and its impact on everyday family life. Parents and carers report that the service does not always appear to recognise the complexities and challenges that neurodivergent children and young people may face, particularly in relation to behaviours, sensory needs, and the pressure this places on family dynamics. As a result, families have shared that they have experienced significant reductions in their packages, often without clear explanation or recognition of their ongoing needs. In many cases, families are then discharged from the Jigsaw service altogether. Understandably, this is leading to growing concern and a sense of vulnerability among families, particularly those who rely heavily on this support to maintain stability and well-being at home.

Children and Families Act 2014 (SEND provision) recognises children with special educational needs and disabilities (SEND), which includes neurodivergent conditions, and provides a framework for assessing and meeting their needs.

COMPLAINTS

In recent months, we have repeatedly heard from families expressing frustration over complaints not being addressed promptly. Social workers often encourage informal conversations as a way to resolve issues; however, many families prefer a formal written record due to their lack of trust in the system and the need for clear documentation of their concerns.

We are also aware that some families are seriously considering pursuing judicial reviews or involving the Ombudsman because they feel their complaints and concerns have not been handled fairly or transparently.

Additionally, while there is a noticeable increase in families experiencing reductions to their short breaks, it appears that complaint responses tend to focus primarily on these cuts. Unfortunately, this narrow focus means that other significant issues raised by families are often overlooked or downplayed, leaving key concerns unaddressed and families feeling unheard.

DUTY LINE

We regularly hear from families that when they call the duty line, their calls are not always answered promptly, and they often face long wait times before speaking to someone. When they do get through, the social care staff member answering the call is frequently unable to provide clear or immediate answers to their questions. While staff often commit to following up and getting back to the family with the necessary information, this follow-up either does not happen or can take several weeks to materialise.

During this prolonged waiting period, families' situations can deteriorate significantly, leaving them feeling abandoned, frustrated, and increasingly vulnerable. This delay in response not only exacerbates stress and anxiety but also risks missing crucial windows for timely intervention. The lack of consistent, reliable communication undermines families' trust in the system and leaves them without the support they desperately need in moments of uncertainty and crisis.

JIGSAW AND HEALTH SERVICES

We have repeatedly heard from families and partner professionals that the Jigsaw team frequently frames concerns primarily as health issues, often insisting that a clinical solution is required before any social care support can be provided. This approach can feel like passing the issue, effectively shifting responsibility away from Jigsaw and onto health services, even when a social care response is appropriate and legally mandated.

This narrow focus on clinical eligibility fails to acknowledge the holistic nature of support required by children and young people with SEND and their families. It overlooks the fact that social care legislation — including the Children Act 1989, the Care Act 2014, and the SEND Code of Practice 2015 — recognises the importance of addressing social, emotional, and practical needs, not just medical or clinical diagnoses. These laws set out local authorities' duty to assess and meet eligible needs arising from disability or SEN, which may not always fit neatly within a clinical framework.

Moreover, families and other professionals report that Jigsaw staff sometimes dismiss or question the validity of reports and assessments from other qualified professionals, such as clinical psychologists, therapists, or independent specialists. This undermines multi-agency working principles central to the SEND Code of Practice, which emphasises collaboration and valuing all professional input to provide a comprehensive picture of the child's needs.

The failure to listen to or trust the expertise of other professionals can delay crucial support, causing distress and frustration for families who are left feeling unheard and unsupported. It creates a barrier to truly person-centred care, which should be driven by an integrated understanding of each child's unique situation rather than rigid clinical thresholds.

This practice is not only damaging to families but also inconsistent with legal duties. The Care Act 2014, for example, requires local authorities to consider the wellbeing of the individual, which includes their emotional and social needs, and to involve them in decision-making. Likewise, the Children and Families Act 2014 mandates a coordinated approach to SEND assessments and provision.

To improve outcomes for children and families, Jigsaw must adopt a more inclusive, flexible approach that respects multi-agency input, recognises the full spectrum of needs beyond clinical diagnoses, and accepts its statutory responsibility to provide appropriate social care support without unnecessary deferrals to health services.

PARENTS HAVING QUALITY TIME WITH SIBLINGS

We have received reports that when parents have expressed concerns about not having enough one-to-one time with their non-SEND children, some Jigsaw professionals have suggested that the parent consider taking the young person out of school for the day. This advice is deeply concerning, especially given the current emphasis by the council on improving school attendance and reducing absences. Removing a child from school not only impacts their education and social development but also places families in a difficult position, potentially conflicting with broader educational policies and safeguarding responsibilities.

It is important to remember that short breaks are a statutory duty of local authorities under the Chronically Sick and Disabled Persons Act 1970 (Section 2) and the Children Act 1989. These laws require authorities to provide appropriate services that support disabled children and their families, with the aim of promoting their welfare, enhancing family wellbeing, and preventing family breakdown. Short breaks should be used constructively to provide families with genuine respite and support—not to inadvertently encourage school absence or disrupt a child's education.

Ensuring families have access to meaningful short breaks that allow quality time for siblings and carers, without compromising educational attendance, is essential. This balance supports the whole family's wellbeing and upholds their rights under the law.

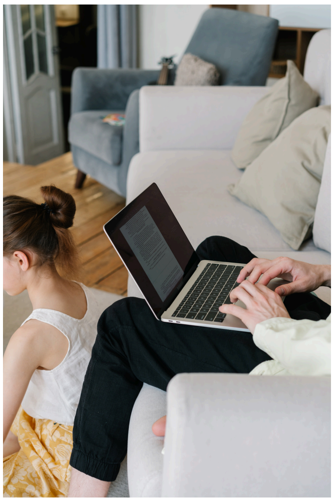
OPPORTUNITIES IN THE CITY

There are very limited opportunities across the city for young people with SEND to participate in activities that are truly inclusive and supportive of their needs. For example, Active Nation, which previously offered SEN-specific sessions, is no longer in operation. This closure has left a significant gap in accessible leisure and recreational options tailored for young people with additional needs.

As a result, families who have Personal Assistants (PAs) supporting their children face a frustrating challenge: there are very few venues or programs where their young person can feel welcomed, safe, and properly supported. Many of the existing activities are not designed with sensory needs or social communication differences in mind, making it difficult or impossible for some young people to cope with busy, noisy, or overstimulating environments.

This lack of appropriate provision restricts young people's opportunities for social interaction, physical activity, and personal development, contributing to isolation and reduced quality of life. It also places additional stress on families and carers, who often have to spend considerable time and effort searching for suitable activities or must forgo opportunities altogether. Without more inclusive, well-supported options, many young people with SEND are being denied the chance to participate fully in community life.

WORKING PARENTS OF SEN YOUNG PEOPLE



Under the Childcare Act 2006, under Section 6, local authorities must: 'Secure sufficient childcare for working parents or those undertaking training, including childcare for disabled children, so far as is reasonably practicable'.

Along with, SEND Code of Practice (2015) though not legislation itself, it is statutory guidance under the Children and Families Act. Paragraph 4.31: Local authorities must include in the Local Offer clear information about 'Childcare, including before- and after-school care and holiday provision. This reinforces the legal duties under the Childcare Act to ensure sufficient and inclusive provision'

Locally, there is a significant and ongoing shortage of after-school provision for young people with SEND, which continues to place immense pressure on families who rely on these vital services for respite, social development, and support. This gap urgently needs to be addressed to ensure equitable access and opportunities for all young people.

As a Parent Carer Forum, we have raised this issue repeatedly with various teams and departments. Unfortunately, there appears to be a lack of clear ownership or accountability, with no one stepping forward to take responsibility for resolving the problem. This leaves families feeling unheard and frustrated, as their practical needs remain unmet.

We initially raised this concern with Jigsaw on 6th March and agreed to pause further escalation while we awaited the return of Tammy, who has a strong understanding of the relevant legislation around SEND after-school provision. Jigsaw had acknowledged their limited familiarity with this area and welcomed Tammy’s expertise to help guide improvements. However, in the meantime, families continue to face uncertainty and lack of provision, highlighting the urgent need for renewed focus and action from all stakeholders involved.

CRS

When families reach a point of crisis, we encourage them to contact the Children’s Resource Service (CRS) if they are not already supported by Jigsaw. However, many Parent Carers feel hesitant or reluctant to reach out, largely due to the overwhelming and often intimidating safeguarding messages they encounter online about CRS. These messages can create fear and uncertainty, making families worry about potential consequences of asking for help.

For those who do find the courage to call, the experience can be frustrating and disheartening. The wait time to speak to someone is often between 15 to 25 minutes, which can feel unbearable when families are already under immense stress. During this long hold, many give up either because they assume other families are in greater need, or because their anxiety and distress make it too difficult to keep waiting. As a result, some families simply hang up without getting the support they urgently require.

This situation leaves families feeling isolated, unsupported, and at risk of crisis escalating further, when timely intervention could have made a significant difference. It is essential that access to CRS is made more approachable, responsive, and reassuring so that families in their most vulnerable moments are not deterred from seeking help.

ONE AND ONLY

In Southampton, the use of the ‘One and Only’ form was introduced with the intention of streamlining support for families. It aims to ensure that professionals across services share key information and that families only need to tell their story once. This is especially important because, for many families, recounting their experiences which often involve trauma, loss, crisis, or long-term stress can be deeply distressing and emotionally exhausting. Repeating the same information to multiple professionals, sometimes over and over, can retraumatise families and lead to disengagement from services altogether.

Nationally, there is a recognised best practice supported by the SEND Code of Practice and safeguarding guidance of assigning one key worker or lead professional to act as a consistent point of contact for the family. This person should coordinate services, advocate for the child and family, and reduce fragmentation across teams. However, in practice, this is not consistently happening in Southampton. Many families are being left to manage complex needs alone or are being passed between services, which leads to confusion, delays, and poor communication.

Increasingly, families tell us that when other children in the family are struggling, or when parental mental health or wellbeing is affected, they are simply told to self-refer to the Children's Resource Service (CRS) or to seek help from universal or voluntary sector support. This happens instead of the allocated social care professional taking responsibility to assess and coordinate the wider family’s needs.

This disjointed approach places the burden of navigation back onto already overwhelmed parents often while they’re in crisis and undermines the very principles of early help and coordinated support. Families need more than a form; they need a joined-up, person-centred system that works with them, not one that creates more stress and complexity.

We urge a refresh of practice in line with national expectations: to deliver on the promise of a single key worker or lead professional, to improve family experiences, and to prevent escalation of need that could be avoided through earlier, more coordinated intervention.

There are 4 key pieces of legislation which support this
1. SEND Code of Practice: 0 to 25 years (2015)
Section 2: Principles underpinning the Code of Practice emphasises the need for coordinated support and reducing the need for families to repeat their stories. Paragraph 2.21 encourages the appointment of a key worker or lead professional to help families navigate the system. “Local authorities should adopt a key working approach, which provides children, young people and parents with a single point of contact to help them navigate the system and ensure that services are co-ordinated around their needs. ”This guidance is non-statutory for health and social care but statutory for local authorities under the Children and Families Act 2014.

2. Children and Families Act 2014
This Act lays the foundation for a more integrated system of support for children with SEND and their families. While it does not specifically require a “key worker,” it underpins the duty for joined-up working between education, health, and care services (Section 26), and for the coordination of EHC assessments and plans. The implication is that someone, often referred to as a key worker, family support worker, or lead professional is needed to ensure the process is family-centred and consistent.

3. Working Together to Safeguard Children (2018)
This statutory guidance highlights the role of a lead professional in coordinating a multi-agency plan under early help or child in need interventions. “Where more than one agency is involved, there should be a lead practitioner (sometimes referred to as a key worker) to act as a single point of contact.” This is especially relevant for families who are not at child protection level, but still need targeted support across multiple services.

4. NICE Guidelines (e.g., NG43 – Transition from children's to adults' services)
NICE also recommends the use of a named worker or coordinator for young people with complex needs transitioning between services, which reinforces the principle of continuity and advocacy.

SUPPORT FOR SIBLINGS

We frequently hear from families that there is a significant gap in support for young carers and siblings who also have additional needs themselves. Many of these young carers face complex challenges, balancing their own health, education, and wellbeing alongside the responsibilities of caring for a sibling with SEND or complex needs.

Families report that the current Young Carers service is often not suitable for these young people, as it is unable to adequately meet their specific and often more complex needs. This leaves young carers without the tailored support they desperately require to manage the physical, emotional, and practical demands placed on them.

Despite existing legislation designed to protect and support young carers, such as the Children and Families Act 2014 and the Care Act 2014, families find that no other local service is stepping in to fill this gap. This lack of appropriate support can have profound negative impacts on young carers, including increased stress, poor mental health, reduced educational attainment, and social isolation. It can also place additional pressure on the whole family unit, as young carers struggle without adequate help or respite.

This situation is concerning because it means that young carers with additional needs are being left behind. Their unique circumstances overlooked, and their rights unmet. To uphold the legal duties owed to them and to safeguard their wellbeing, it is essential that local services review and improve their provision to ensure young carers with additional needs receive equitable, responsive, and tailored support.

Under Children Act 1989 – Section 17 (Child in Need), local authorities have a duty to assess and support children in need, and young carers are explicitly included in this category when their caring responsibilities impact their health, development, or education.
Section 17(10) defines a child as being "in need" if:

- They are unlikely to achieve or maintain a reasonable standard of health or development without the provision of services by a local authority,
- Their health or development is likely to be significantly impaired without such services, or
- They are disabled.

Therefore, a CIN assessment under Section 17 can be triggered for a young carer based on these criteria.

However, when families try to access a Child in Need (CIN) assessment for a sibling particularly when that sibling is a young carer who also has special educational needs (SEN) they are often passed from one service to another. Families report being told that the Jigsaw social worker should complete the assessment, while Jigsaw staff respond that their role is solely to support the disabled child, not their siblings.

This lack of clarity and accountability is leaving families stuck in the middle, with no one taking responsibility for assessing the needs of vulnerable young carers. The situation is even more concerning for children under the age of 8, as they fall outside the age range of the Young Carers service and often receive no support at all despite clearly taking on inappropriate levels of responsibility at home or escalating needs of their own.

Parents are left feeling helpless and unheard, watching the sibling struggle emotionally, socially, or academically while trying to care for their sibling. These children some as young as four or five are taking on roles far beyond their years to support their sibling yet are left invisible to the system.

Families are asking for support not just for the child with SEND, but for the whole family unit and too often they're told "that's not our role." This results in emotional burnout for parents, worsening mental health for young carers, and a breakdown of trust in the services meant to help.

There needs to be a clear, joined-up approach, where a child's needs are recognised holistically and assessments are not delayed due to professional disagreements about who should take responsibility. The impact on families is real, and the system must do better to ensure no child is left unsupported simply because they fall between services.

SUMMER HOLIDAYS

As we approach the summer holiday period, a growing number of families are expressing deep concern and anxiety about how they will manage without sufficient support. The significant reductions in short breaks and the limited availability of HAF (Holiday Activities and Food) spaces are placing immense pressure on families who rely on these vital services for respite and stability.

Additionally, the decline in available courses and programs means many families lose access to crucial peer support networks—connections that provide emotional support, shared experiences, and practical advice. This loss can leave families feeling isolated and overwhelmed, increasing stress levels and reducing their capacity to cope.

We are deeply concerned that these combined factors will lead to a sharp rise in family crises during the summer, a concern that was openly discussed at the recent SEND Partnership Board. Without adequate and accessible support, families may face heightened risks to their wellbeing and that of their children, with potential knock-on effects on mental health, family relationships, and access to education and social opportunities.

Urgent action is needed to address these gaps and ensure families have the resources and support they require to navigate what should be a joyful and restorative time for young people and their carers.

LEGISLATION IN GENERAL

While we fully recognise that the legislation around social care and short breaks can be complex and at times confusing for both families and professionals it’s important that we remain focused on what the current law requires right now.

Under Section 2 of the Chronically Sick and Disabled Persons Act 1970, if a child has an identified and documented need for services such as short breaks, practical assistance, or support in the home, the local authority has a legal duty to provide those services. This is a mandatory duty not optional or dependent on available funding.

Therefore, if services are reduced, delayed, or withheld purely because of budget constraints, staffing issues, or waiting lists, this could represent a breach of statutory duty. Financial pressures or internal service limitations do not override the law. The duty to meet need remains and families should not be left without vital support because of behind-the-scenes resource decisions.

We are aware that the Government is currently reviewing and consulting on changes to how social care and short breaks are delivered, in an attempt to simplify and update existing legislation. However, these changes are not yet in place. The reforms are still in the drafting stage, and will go through a formal public consultation process before being reviewed, debated, and passed by Parliament or Cabinet.

Until then, the current legal duties stand. Families must continue to be supported in line with existing law particularly the protections outlined in the Chronically Sick and Disabled Persons Act and any departure from that should be challenged to ensure that children receive the support they are entitled to.

CONCLUSION

Families of children with SEND in Southampton face systemic challenges that negatively impact their access to vital services, including short breaks, assessments, and ongoing social care support. The current model is often seen as fragmented, non-transparent, and reliant on rigid diagnostic criteria rather than a holistic, needs-led approach. This results in inequities where some families receive less support or face unnecessary barriers.

There is a clear mismatch between legislative intentions and lived experiences, with many families feeling unheard, unsupported, and overwhelmed especially during critical times such as school holidays or crisis points. The lack of accessible after-school and community provision further limits opportunities for children and young people to thrive outside the home.

The way complaints and appeals are handled erodes trust and can leave families feeling isolated and disenfranchised. Without meaningful co-production and engagement, policies risk failing those they aim to support.

For Southampton to meet its statutory duties and truly support families, a fresh, collaborative approach is essential one that prioritises clear communication, fairness, and comprehensive support tailored to diverse needs.

RECOMMENDATIONS

1 Co-Production and Transparency

- Ensure all new policies, including short breaks and direct payment policies, are co-produced with Parent Carer Forums at every stage, with accessible consultation opportunities beyond online platforms for families.
- Provide clear, transparent communication about policy changes, assessment criteria, and appeals processes.

2 Needs-Led Assessments

- Adopt a holistic, needs-based assessment framework that prioritises functional needs over diagnostic labels, especially for early identification of learning disabilities and neurodivergence.
- Ensure timely and consistent assessments through Jigsaw and CRS, with clear pathways and defined eligibility criteria.

3 Equitable Access to Short Breaks and Respite

- Address gaps in short break provision, including increasing availability during school holidays and half-terms, improving transport support, and expanding specialist play and after-school opportunities.
- Review and adjust direct payment systems to fairly reflect the needs of children requiring 2:1 support.

4 Support for Young Carers and Siblings

- Develop targeted support services for young carers who also have additional needs, ensuring their requirements are acknowledged and met in line with relevant legislation.

5 Improved Complaints and Appeals Process

- Streamline and improve responsiveness of complaints handling, ensuring families’ concerns are formally documented and addressed fairly and promptly.
- Provide additional support for families less confident in navigating the system to ensure equity in appeals outcomes.

6 Strengthen Family-Cantered Approaches

- Implement and embed a key worker or single point of contact model to reduce the burden on families to repeatedly share their stories and to provide coordinated support.
- Ensure support plans facilitate quality time for all children in the family, recognising the importance of sibling relationships.

7 Address Transport and Accessibility Barriers

- Provide funding or support for transport to short breaks and community activities, particularly for families living further from service locations.

8 Expand Community Provision

- Encourage and support local businesses and organisations to develop SEND-friendly activities with smaller group sizes and sensory-friendly environments.

KEEP IN CONTACT FOR UPDATES

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