APPENDIX CONTENTS PAGE

Appendix 1 - Survey Questions (chronological order of survey)

1. Did you know that as a parent/carer of a disabled child you have a legal right to request a Parent Carer Needs Assessment?
2. Please only complete the remaining questions if all of the following apply:
    - You requested a Parent Carer Needs Assessment since January 2025
    - Your child/young person is under 16 years old
    - Your child/young person is NOT under the Children with Disabilities Team
3. Have you requested a Parent Carer Needs Assessment since January 2025?
4. Did you face any barriers when trying to get an assessment?
5. If you received a final report of the assessment, were your needs clearly recognised?
6. Were you offered any support or services?
7. Has having an assessment made your caring role easier?
8. How satisfied are you with the assessment process?
9. Would you like to share more about your experience?
10. How did you first learn about your right to request an assessment?
11. How easy was it to request an assessment?
12. How long did it take from request to completion?
13. Did you experience any of the following challenges?
14. What was the biggest barrier or challenge you faced?
15. Did the assessor demonstrate an understanding of disability & caring challenges?
16. Areas covered by the PCNA (list given)?
17. The assessor explained the process and next steps clearly?
18. Were your needs clearly identified?
19. Did you receive a written support plan?
20. What support or services were agreed?
21. Have you received the agreed support?
22. Did the assessment improve your wellbeing?
23. Has the assessment improved life for your family overall?
24. What positive changes have you experienced since the assessment?
25. If your needs weren't recognised, why do you think that happened?
26. What one change would improve assessments for parent carers?
27. Is there anything else that would have made you feel more understood?
28. Would you like to be contacted to give more information?

Appendix 2 - Awareness of PCNA

Please note that:

Q1 refers to Question 1 etc., and numbers in brackets after each percentage e.g. *(5) refers to the actual number of responses recorded*.

Question 1

Did you know that as a parent carer of a disabled child you have a legal right to request a PCNA?

Survey Response: (206 responses, 2 skipped**)**

- 25% Yes (52 people did know you have a legal right to a PCNA)
- 75% No (154 people didn't know you have a legal right to a PCNA)

Analysis of Responses

A significant majority of parent carers (75 %) are unaware of their legal right to request a PCNA.

This indicates low statutory awareness, which may prevent families accessing support and may reflect weaknesses in communication pathways from the local authority and partner agencies.

Question 10

How did you first learn about your right to request an assessment?

Survey Responses: 20 respondents (multiple-choice question; participants could select more than one option)

- 25% Internet/social media (5)
- 25% Another parent/ word of mouth (5)
- 20% School/SENCO (4)
- 10% General Practitioner or other health professional (2)
- 5% Social Services/ Local Authority (1)
- 20% Other (please specific) (4)

Appendix 2 - Awareness of PCNA (continued)

Analysis

Most awareness comes from informal routes rather than official ones.

- 50% of respondents first learn about their right to request an assessment from Internet/social media or another parent/ word of mouth. This indicates that parent carers are actively seeking out this information.
- 30% became aware through official routes like school/SENCO or the GP/ other health professionals.
- Only 5% found out through social services or local authority, despite these organisations being responsible for conducting PCNAs and offering the support.

Quote Box- Other ways in which respondents first learnt about their right to request an assessment:

This survey. (refers to participating in this survey).
Your newsletter. (refers to Healthwatch Worcestershire Newsletter).
Sendiass. (Refers to Special Educational Needs and Disabilities (SEND) Information, Advice and Support Service (IASS) covering Hereford and Worcestershire).

Recommendation

- Improve proactive communication from the local authority and health professionals.
- A proactive information campaign (schools, GPs, early help, social media) would help increase awareness.
- A clear, accessible factsheet should be produced explaining the rights and eligibility for a PCNA.
- A clear pathway should also be published for parent carers who request an assessment. At present, families may be diverted to Early Help or other services without their original PCNA request being properly addressed.
- Universal services should routinely inform parent carers of their entitlement to a PCNA.

Appendix 3 - Process of Requesting a PCNA

Question 3

Have you requested a PCNA since January 2025?

Survey Responses (Responses 27, Skipped 181)

- 22% Yes, and it went ahead (6)
- 26% Yes, but my request was declined (7)
- 37% No, I didn’t know I could (10)
- 15% No, for another reason (please specify) (4)

Quotes – Other comments

We had an early assessment instead
I have requested one but Jan 2026 after seeking advice
I did request but I chose not to go ahead in the end
I have been asking for a while and was told I'd be called back several times but haven't been contacted so have given up

Analysis in terms of the processes of requesting a PCNA

One-fifth of those who met the criteria went ahead with an assessment.
A quarter of respondents reported that their request was declined; however, the survey did not ask why, so the reasons remain unknown.
Two-fifths of those who did not request an assessment cited a lack of awareness.
15% did not request an assessment for other reasons, listed above.

Recommendation

Produce a clear and transparent written explanation of the eligibility criteria for accepting or declining applications. At present, the only legally defined criterion is that the applicant must be providing care for a disabled child.

Appendix 3 - Process of Requesting a PCNA (continued)

Question 11

How easy was it to request a PCNA? (Rate on a sliding scale)

Survey Responses (17 respondents)

- 47% Difficult (8)
- 12% Somewhat difficult (2)
- 23% Neutral – not easy or hard (4)
- 0% Somewhat easy (0)
- 18% Very easy (3)

Analysis
Parents generally found the request process difficult. Responses clustered around "difficult" and "neutral."

Recommendation

Simplify the request mechanism (e.g. paper-based form, online form, clear steps).

Provide guided support for first-time applicants.

Appendix 3 - Process of Requesting a PCNA (continued)

Question 12

How long did it take from requesting a PCNA to completion?

Survey Responses: (17 Respondent)

- 12% 2–4 weeks (2)
- 18% Over a month (please specify how long) (answer below) (3)
- 70% Never carried out (12)

Analysis

The overwhelming majority report no assessment was completed.

- 12 out of 17 respondents never completed a PCNA, a considerable high number compared to those who did get assessed.
- 2 out of 17 respondents reporting it took 2-4 weeks.
- 3 out of 17 respondents reported it took over a month, with details and specified below.

Quote Box – Other comments regarding how long PCNA took?

Over a month but can't remember precisely
About 5 months
Currently waiting

Recommendation

When a service, support request, or application is declined, families must not be left without guidance or options. Providing clear pathways means establishing a transparent, structured, and compassionate process that helps families understand:

1. Why the decision was made,
2. What they can do next, and
3. Where they can go for alternative support or further help.

Investigate bottlenecks preventing timely completion.

Introduce tracking and monitoring for assessment timeliness.

Appendix 4 - Barriers to Access

Question 4

Did you face any barriers when trying to get an assessment? (Select all that apply)

Survey Responses: 27 respondents, multiple answers selected

Top barriers included:

- 30% I didn't know I had a legal right (8)
- 30% I didn't know how to request one (8)
- 26% Process was unclear (7)
- 22% Long waiting times: (6)
- 11% My request was declined and I did not understand the reason (3)
- 22% I did not receive enough information to understand the process (6)
- 19% Concern about being judged or misunderstood (5)
- 15% I was told I was not eligible / redirected elsewhere (4)
- 4% I didn’t face any barriers (1)
- 33% Other (please specify) (9)

Analysis

The most common barriers relate to information gaps:

- 30% did not know they have the legal right to request a PCNA.
- 30% did not know how to request one.

The second most common barrier were misunderstandings about the process:

- 26% said the process was unclear.
- 22% stating they did not receive enough information to understand the process.

The next biggest barriers was the long waiting time, a barrier for 22% of respondents.

Additionally, 19% of parent carers expressed an emotional barrier of their concern about being judged or misunderstood.

Appendix 4 - Barriers to Access (continued)

Quote Box - Other barriers, please specify

I felt like I was interrogated as to why I wanted one. Even when agreed I was told because we had a referral into Early Help we had to wait for that.

When I had the assessment the assessor didn't seem to know what they were doing and finished the assessment incomplete saying they didn't think it was the right thing for me.

(A lack of) understanding of SEN/Autistic burnout by initial social worker completing assessment.

When I worked out who to ask I was told that my son (on mid rate DLA) wasn’t disabled enough for me to qualify.

I wasn’t informed by the school I could do this for my child.

Request by email ignored by social services.

Was told and have this in an email that it would not involve a budget or respite as it was a signposting service.

Waited 7 weeks for call back. Rang again and they wanted to assess but I chose to not go ahead as I didn't like their attitude.

I kept being told I'd receive a call. Have chased twice and left messages but still haven't had a call.

Recommendation

Publish a step-by-step guide to the PCNA process.

Provide reassurance messaging reducing stigma and fears of judgement.

Improve clarity around waiting times and next steps.

Appendix 4 - Barriers to Access (continued)

Question 13

Did you experience any of the following challenges?

Survey Responses (15 responses, multiple answers selected)
Key challenges:

- 7% I didn't experience any barriers or challenges (1)
- 7% Language or communication barriers (1)
- 20% Difficulty understanding paperwork (3)
- 20% Communication from the assessor was unclear or insufficient (3)
- 20% The assessment did not fully reflect my need (3)
- 47% Lack of clear next-step information (7)
- 47% Other (7)

Analysis
Most challenges relate to communication and clarity of guidance provided to parent carers.

Quote Box - Other challenges experienced by the parent carers

Knowledge and understanding of SEN needs from assessor
It is extremely hard to get to see any assessor
Request ignored by social services
Not completed as couldn't offer a proper legal assessment
Long wait
No one returned the call I was promised

Recommendation

Implement communications training for assessors.

Provide a simple, accessible outline of next steps.

Appendix 4 - Barriers to Access (continued)

Question 14

What was the biggest barrier or challenge you faced through the PCNA process? (open-ended questions)

Survey Responses (14 responses)

Lack of guidance

- Assessment left incomplete. It felt like there wasn't any help available. I had to push for the assessment and then was told that I needed a child in need assessment instead. I was vaguely offered support but only on the basis of me coming up with what I need with no guidance on what was possible or available.
- Repeatedly requesting carers assessment and being signposted in different directions. When assessed I thought it was a carer assessment but instead it was an assessment of child needs. Have requested carer assessment again - been told they need to speak to their manager to see if it can happen.
- Not understanding what I'm entitled to or not.
- Waiting and not knowing what I'm waiting for
- Lack of any communication, frequent promises, inappropriate support suggestions that wouldn't help
- Not being told what this is about?
- Knowing who to ask for the assessment.

Lack of support for those with language barrier

- I feel I wasn't given the time and understanding due my background where for most women English language is a barrier

Actively discouraging the parent carer

- Telling me it was not worth doing because I would not get any help

Social services issues

- Social services ignores & does not reply to my emails (for the last 2 years) despite being CIN since 2024, Child Protection since Dec 2024 & now PLO.
- Not being assessed as told before assessment that they could only offer signposting.
- First question on the phone to even get to ask for an assessment was what family help do you have. What has that got to do with it?

Recommendation

A thematic analysis should be applied to identify and clarify key patterns within the challenges described.

Appendix 5 - Communications

Question 17:

The assessor explained the process and next steps clearly.

Survey Responses (13 responses)

- 0% Yes (0)
- 100% No (13)

Analysis

Every respondent said the process and next steps were not explained clearly.

Recommendation

Produce a mandatory "explain next steps" script or checklist.

Appendix 5 - Communications (continued)

Question 27

Is there anything else that would have made you feel more understood? (open ended question)

Survey Responses (9 responses)

- The initial contact was quite rude and made me feel like I was just out for whatever I could get. The actual assessor was much more friendly and professional. I still don't fully understand why I didn't qualify.
- The first communication not coming in the form of a survey
- We shouldn't be judged based on the culture or ethnicity. Everywhere it’s preaching that rules are equal but in reality nothing is same.
- My needs were minimised because our son has a mental disability, not a physical disability. It’s still bloody hard to manage him and keep him safe even though we don’t use a hoist or a wheelchair. It’s difficult in different ways.
- Have emails read & responded to.
  Social Work team have ANY neurodivergence training, ideally up to date training or refer our case to a team that HAS neurodivergent training.
- Above - realising how difficult being a carer actually is.
- Nobody at WCC truly understands learning disabilities.
- Not being made to feel like a number in a queue, don't feel like a priority at all and am struggling
- Working with teams I was already working with. Adding more people and having to keep saying I'm struggling is distressing. Why is everything contracted out why can't the same teams who understand my child's situation and mine do the assessment. They’re the ones who said I should apply for one

Analysis

Responses highlight significant communication and empathy gaps. Recurring themes include:

- Experiences of feeling judged and lack of cultural sensitivity
- Lack of understanding of learning disabilities and neurodivergence
- Poor responsiveness to emails and communication

Recommendation

Implement trauma-informed, culturally competent, and carer-sensitivity training for assessors.

Appendix 6 - Quality of Assessment

Question 5

If you received a final report of the PCNA, were your needs clearly recognised?

Survey Responses (27 respondents)

- 0% Yes, in detail (0)
- 4% Yes, but only vague (1)
- 30% No, I didn’t receive a copy (8)
- 7% Not sure: (2)
- 59% N/A: (16)

Analysis

Only one person received a final report from their assessment, out of the six people who had requested one.
30% did not receive a copy of the final assessment report.
This suggests the system does not consistently produce or share final reports.

Recommendation

Standardise the issuing of written assessment outcomes.
Ensure every assessment results in clear documentation being provided to the parent carer.

Appendix 6 - Quality of Assessment (continued)

Question 15

Did the assessor demonstrate an understanding of disability and caring challenges? (Rate on a sliding scale from 1 to 5)

Survey Responses (14 respondents)

- 0% Strongly agree (0)
- 21% Agree (3)
- 21% Neutral (3)
- 15% Disagree (2)
- 43% Strongly disagree (6)

Analysis

Responses indicate that many parent carers felt the assessor did **not** understand disability and caring challenges.

The highest combined scores were "disagree" and "strongly disagree" (57%), while 42% expressed some level of agreement.

0% chose "strongly agree," indicating a widespread lack of confidence in assessors' understanding.

Recommendation

Provide mandatory training for in-depth disability-awareness and for carers-rights.

Training should go beyond basic disability awareness and include a deeper understanding of how caring responsibilities affect families and their circumstances.

Appendix 6 - Quality of Assessment (continued)

Question 16

What areas were covered in the Parent Carer Needs Assessment? (multiple answers allowed)

Survey Responses (12 respondents)

Yes was covered in Parent Carer Needs Assessment

- 0% Your physical health
- 0% Your emotional wellbeing
- 9% Your employment or education (1)
- 0% Access to short breaks or respite
- 0% Your ability to have a life outside of caring

Partially was covered in Parent Carer Needs Assessment

- 27% Your physical health (3)
- 18% Your emotional wellbeing (2)
- 18% Your employment or education (2)
- 18% Access to short breaks or respite (2)
- 8% Your ability to have a life outside of caring (1)

No was not covered in Parent Carer Needs Assessment

- 73% Your physical health (8)
- 82% Your emotional wellbeing (9)
- 73% Your employment or education (8)
- 82% Access to short breaks or respite (9)
- 92% Your ability to have a life outside of caring (11)

Analysis

Needs are not being consistently explored during assessments.
Across all areas (physical health, emotional wellbeing, employment/education, access to respite, and life outside caring), the majority of respondents reported “No”.

Recommendation

Introduce a structured assessment template ensuring key domains are covered.

Appendix 6 - Quality of Assessment (continued)

Question 18

Were your needs clearly identified?

Survey Responses (14 Responses)

- 0% Yes, in detail (0)
- 7% Yes, but only vaguely (1)
- 93% No (13)

Analysis
Assessment outcomes rarely identified needs clearly.
The vast majority (13 out of 14 respondents) said their needs were **not** clearly identified.

Recommendation

Improve assessment quality assurance processes and strengthen reflective supervision for assessors.

Question 19

Did you receive a written support plan?

Survey Responses (13 responses)

- 0% Yes (0)
- 92% No (12)
- 8% Not sure (1)

Analysis
Written support plans are almost never issued.

Recommendation

Make written support plans mandatory for all completed assessments.

Appendix 7 – Outcomes

Question 7

Has having an assessment made your caring role easier?

Survey Responses (27 respondents)

- 4% Yes (1)
- 4% A little (1)
- 18% No difference (5)
- 4% Made harder (1)
- 70% Not applicable (19)

Analysis

The PCNA currently has minimal positive impact on carers

- Only two respondents reported some positive impact.
- Five respondents said the assessment made no difference.
- One respondent reported that the assessment made their caring role harder.

A limitation of this data is the small sample size, which may reflect the low number of completed assessments since January 2025.

Recommendation

Strengthen the assessment process to produce meaningful support outcomes.

Ensure follow-up support is implemented.

Appendix 7 – Outcomes (continued)

Question 8

How satisfied are you with the assessment process?

(Rate your experience on a scale of 1 to 5)

Survey Responses (21 Respondents)

- 48% Very dissatisfied (10)
- 24% Somewhat dissatisfied (5)
- 14% Neutral (3)
- 0% Somewhat (0)
- 14% Very satisfied (3)

Analysis
Overall satisfaction is low. 72% of ratings fall between “Very dissatisfied” and “somewhat dissatisfied”.

Recommendation

Conduct a quality review of assessor training, communication, and process. Use this score as a baseline measure for improvement.

Question 22

Did the assessment improve your wellbeing?

Survey Responses (12 respondents)

- 0% Yes (0)
- 92% No (11)
- 8% Unsure (1)

Analysis
The responses reflect that the current PCNA does not improve the parent carers wellbeing, with one person being unsure if it made an improvement.

Recommendation

Re-examine the purpose of assessments and strengthen pathways that enable wellbeing improvements.

Appendix 7 – Outcomes (continued)

Question 23

Has the assessment improved life for your family overall?

Survey Responses (12 respondents)

- 0% yes
- 0% a little
- 75% No difference (9)
- 25% Made things harder (e.g. Increased workload, stress, unmet expectations) (3)

Analysis

Respondents reported no improvements for their families.

- 75% reported no difference, suggesting limited value in completing a PCNA.
- For some families, assessments made circumstances harder, possibly due to increased workload, stress, or unmet expectations.

Recommendation

Introduce realistic expectation-setting discussions early in the assessment process.

Appendix 7 – Outcomes (continued)

Question 24

What positive changes have you experienced since the assessment?

Survey Responses (5 respondents)

- 0% Improved emotional wellbeing
- 0% Better access to respite
- 0% Reduced Stress
- 0% Improved family relationships
- 100% Other selected (5)

Analysis

All listed positive outcomes received zero responses.
Respondents instead used the “Other” option to provide narrative feedback.

Quote box

Other positive changes have you experienced since the assessment

> I'm hoping to get back into work but that means more stress lol.
> Things got harder because we felt let down.
> None. Other than feeling unsupported by the very system that told me to apply.

Recommendation

Develop a document outlining examples of positive changes that can realistically result from undertaking a PCNA, to support expectation-setting and transparency.

Appendix 8

Case study One: Parent Carer discontinued the PCNA process

My name isn't important, but my situation is one that many parent carers will recognise. I work full time, and I'm also a parent carer to three children, two of whom have complex needs and significant learning disabilities. Managing work, childcare, appointments, and the emotional load of caring is already a huge juggling act — and that's before you try to navigate the support systems that are supposed to help.

How I First Heard About Parent Carer Needs Assessments

I didn't find out from any professional that I had a legal right to request a Parent Carer Needs Assessment. In fact, no one has ever mentioned it to me formally. I only learned about it through other parent carers in Facebook groups. People would post things like, "Did you know you can ask for an assessment?" That was the first time I'd ever heard of it.

It felt strange to realise something so important was never communicated by the services that work with families like mine.

Trying to Request an Assessment

I did decide to request one, early in the summer of 2025, because I was desperate for holiday childcare so that I could keep working. I wasn't looking for respite in the traditional sense — I just needed childcare that would allow me to stay in my job. Without that, I wouldn't be able to pay my mortgage or keep our family stable.

The process immediately felt confusing. The name of the contact point (Family Front Door) didn't make any sense if you were a parent carer. When I rang, the first question I was asked was whether I had family support — before they even took my name. It felt judgemental and dismissive, especially because I wouldn't be calling unless I had already reached the end of my options.

Still, I gave all my details and was told it would be passed to the right team.

Then nothing happened.

Seven weeks later I chased it, only to be told they had no record of my call. All my information had been lost. No explanation, no apology, nothing. That was a huge red flag for me — both in terms of competence and how safely my data was being handled.

Appendix 8 (continued)

Case study One: Parent Carer discontinued the PCNA process

Unexpected and Uncomfortable Contact

After giving my information again, the next contact I received wasn't a letter, an email, or anything official. It was a WhatsApp message from someone I'd never spoken to before. I had never consented to being contacted through WhatsApp. I didn't even know who this person really was beyond a name in a message.

That made me uncomfortable. It didn't feel professional or safe, and it certainly didn't build trust.

Why I Eventually Chose Not to Continue

While all this was happening, I was speaking to other parents whose children have similar needs to mine. They shared their experiences of assessments, reviews and reports — and frankly, it frightened me.

I heard about processes that felt parent-blaming, not child-centred. I heard about being judged for not engaging with activities that simply weren't suitable for their child. I heard about reports that portrayed parents negatively for things outside their control.

I realised that if I had truly understood what the process involved, I might never have tried to request it in the first place.

In the end, I decided not to proceed. I didn't want social care involved in my family. I didn't trust the system, and I didn't feel safe within it.

What It's Like Navigating Support Locally

Support locally is extremely limited, especially for children with higher needs. Activities and services are mostly designed for children with lower levels of disability. My children, who require more intensive support, are often left with nothing appropriate.

The more complex your child's needs are, the harder everything becomes — and the more you seem to be judged for it.

Only one holiday club in the whole area can take my children, and when they open bookings, everyone has to scramble to try to get a place. Even if I combine all my annual leave with my partner's, we still end up short and have to take unpaid leave.

Appendix 8 (continued)

Case study One: Parent Carer discontinued the PCNA process

Family support isn't an option either. Elderly relatives aren't physically able to manage the children's needs, and working relatives aren't available. We are on our own — like so many families are.

The Emotional and Practical Impact

Being a parent carer carries an inherent level of stress. But add in the uncertainty about the future, the pressure of holding down a job, the fear of what might happen if support falls apart, and the daily negotiation of logistics — it becomes overwhelming.

It puts huge strain on relationships. It affects mental health. Some parents, I know, are operating far past breaking point simply because there is no alternative.

What Would Make a Difference

- A lack of clear, accessible information
- No published process explaining what to expect
- No transparency about typical outcomes
- Poor communication
- Defensive attitudes and a culture that doesn't feel collaborative
- A system that seems designed to confuse rather than support

If services were more open about what the process involves, what questions will be asked, what support is typically offered, and what parents should realistically expect, it would help enormously.

Most of all, families want to feel safe, respected, and understood.

My Final Reflection

I work full time. I have three children with complex needs. I'm continually trying to hold my family together while navigating systems that feel as though they were never designed for families like mine.

I know I'm not alone — and that's the saddest part. So many parents share these experiences. And while our stories might differ, the themes are the same: confusion, fear, exhaustion, and a deep desire to be heard.

This case study is just one story — but it represents many.

Appendix 9

Case Study Two: Parent Carer informed does not qualify for a PCNA

I’m a parent carer with several children who have additional needs, and over the years I’ve learned more from other parents than from any professional service. I first heard about Parent Carer Needs Assessments through other parent carers in my yoga group. Until then, I didn’t even know such assessments existed.

How I First Heard About Assessments

I attend a weekly parent carer yoga group, and one week people started talking about carers assessments and the fact that parent carers were able to apply for support. That was the first time I realised there was anything I might be entitled to. A few of us applied together and, at the time, I ended up being awarded some wellbeing funding because of caring responsibilities for my older child.

I had no idea these assessments were a legal right — nobody ever told me that.

Trying to Apply Again

Later, in 2025, I tried to apply again, but this time for support linked to my younger children. I contacted a local carers support charity because that’s who I had spoken to previously. They booked me in for a phone appointment several weeks after my call.

Right from the start, the experience felt very different to the previous year. I didn't feel welcome. The first person I spoke to seemed almost frustrated that I was calling, as if I was asking for too much. It made me feel like requesting help was an inconvenience.

When the assessment finally happened, it was over the phone again. No home visit, no face-to-face meeting — just a conversation lasting about 30 to 60 minutes. They asked the standard questions about my situation, income, circumstances, and so on.

What I Was Told

After the assessment, I was told I didn’t qualify for any financial support this time. Instead, I was referred to a “back-to-work” scheme because I had recently been diagnosed with a disability myself. That was the only outcome from the whole process.

Nothing was offered in terms of respite, wellbeing funding, or practical help. It felt as though the assessment had already been decided before I even had the appointment.

I don’t remember receiving a written report or support plan, and if I did, it didn’t feel meaningful or clear.

Appendix 9 (continued)

Case Study Two: Parent Carer informed does not qualify for a PCNA

How It Made Me Feel

Honestly, the process didn't improve anything. I am burnt out, overwhelmed, and financially struggling. Caring responsibilities, navigating school issues, managing multiple diagnoses, and trying to survive day-to-day already take everything I have.

I just want to live a normal life and have access to the same support other families seem to have. Instead, everything feels like a battle. I'm exhausted before I even begin most days.

What Would Make This Better

If Parent Carer Needs Assessments are a legal right, then they should be automatic. Parent carers shouldn't have to hunt for information, chase assessments, or figure out confusing processes. We have enough on our plates — constantly juggling appointments, paperwork, phone calls, school meetings, and crises.

It would also help to have:

- A clear, consistent process
- Face-to-face assessments
- Proper explanations of what is available
- Decisions that feel fair and not based on the time of year
- Support that acknowledges how draining caring responsibilities can be

Not Just Me

When I fed back to my yoga group, others said they had similar experiences this year — long waits, confusing information, and very little support being offered. It wasn't just me. It seemed to be happening to lots of parent carers at the same time.

There are around twelve parents in my group, and several had assessments around the same period. None of us seemed to receive meaningful support this year.

Final Thoughts

Being a parent carer is already mentally, emotionally, and financially challenging. I spend every day managing children with additional needs, handling crises, trying to hold my household together, and dealing with my own diagnosis. I am doing all of this with limited support and while grieving the loss of key family support I once had.

Appendix 9 (continued)

Case Study Two: Parent Carer informed does not qualify for a PCNA

The assessment process didn’t help. It didn’t relieve any pressure. If anything, it reinforced how hard it is for parent carers to access the help we’re legally entitled to.

All I want is a system that understands the reality we live in — one that supports us, rather than leaving us feeling like we’re on our own.

Appendix 10

Case Study Three: Parent Carer still waiting for an PCNA

I am a parent carer to two children who both have additional needs. I am also neurodivergent myself, so managing daily life, emotional wellbeing, and navigating services takes a lot of energy. I try very hard to advocate for my children and for myself, but it often feels like no one is listening.

How I First Requested Support

I first made a written request for a Parent Carer Needs Assessment in late 2024. After that, throughout early 2025, I repeatedly asked my social worker verbally for a Parent Carer Needs Assessment for myself and for the benefit of my children. I asked many times over several months.

Every request was ignored. Each time I raised the question, my social worker would change the subject or simply not respond. I was never given any explanation or follow-up. I never received a single written response, nor even a verbal acknowledgment.

Being Left Without an Assessment

Despite asking again and again, I never received a Parent Carer Needs Assessment. I wasn’t told why. My needs were never explored. No one ever asked me what support I required as a parent carer.

Because I am autistic, I worked with an advocate (I paid privately) to document my needs clearly — things like communication adjustments, what helps me understand information, and what support I need to take part meaningfully in processes. I submitted this to social care, but it was also ignored.

It felt like nothing I said mattered.

Requesting Specialist Support

I specifically asked to be referred to a neurodivergent adult support team and asked for a social worker with neurodiversity-specific training. I repeatedly explained that my own neurodivergence affects how I communicate and process information, and that my children’s neurodivergence adds complexity to our situation.

These requests were dismissed without explanation. No support was offered.

Appendix 10 (continued)

Case Study Three: Parent Carer still waiting for an PCNA

Other Support We Received

Because we were under safeguarding processes, we did have a family support worker visit for a short time. However, the sessions were not about my needs as a carer. Instead, they focused on parental conflict and included unhelpful messages telling me to “compartmentalise” my safeguarding concerns — even when my children were expressing fear, distress, and showing behavioural changes after contact visits. This advice left me feeling invalidated and unsupported.

Being Left in Limbo

Later in 2025, we were placed in a formal safeguarding process that required parenting assessments. However, my social worker went off sick, and since then nothing has happened. No assessments, no communication, no updates. We are stuck in limbo, expected to continue a process with no guidance or clarity.

I repeatedly asked for written information because I need structure and predictability to manage stress and understand decisions. But even these basic requests were ignored.

Conflict With the Children’s Other Parent

Our family situation is complicated by significant conflict with my children’s other parent. In the past, they agreed with professional assessments and recommendations. But after communication broke down, they began rejecting the children’s diagnoses and refusing medication, accusing me of “medicalising” them.

Professionals have confirmed that the children do have neurodivergent needs. They have assessments, reports, and education plans to evidence this. But when the other parent rejects these needs, it creates huge emotional and behavioural fallout — and I am left to pick up the pieces. This conflict makes everyday life harder and adds pressure to an already overwhelming situation.

My Children’s Needs

Both my children have neurodivergent profiles. They experience sensory processing differences, communication differences, and high levels of emotional distress. One child needs medication to function and feel regulated, which has made a dramatic positive difference — but the other parent refuses to administer it during their visitation time.

Appendix 10 (continued)

Case Study Three: Parent Carer still waiting for an PCNA

At home, I work hard to understand and support their sensory needs. I use a neuro-affirming approach: validating their feelings, helping them recognise internal signals, and finding strategies that meet their needs without overwhelming others. All of this takes energy, constant awareness, and a lot of emotional labour.

My Own Burnout and Recovery

In 2023, I experienced a severe autistic burnout. My nervous system completely crashed. I couldn't function, work, or manage daily tasks. My partner had to take over everything. Since then, I've worked extremely hard to recover with therapy, medication, advocacy support, and self-education. I've rebuilt myself from the ground up — but the ongoing system stress makes it difficult.

Where I Find Support

I get support mostly from other parent carers — including home education groups and, more recently, a local parent carer forum. Being able to talk with people who understand this life is invaluable. It helps me feel less alone, less like I'm "fighting uphill" every single day.

What Would Make a Difference

If I could change one thing, it would be this: Parent Carer Needs Assessments should be carried out by professionals who are properly trained in neurodiversity, trauma, sensory processing, and family complexity. Without this training, they misunderstand our needs, misinterpret behaviours, and leave us without any practical help.

Carer assessments should also be accessible, timely, and taken seriously. Parents shouldn't have to beg for support or chase endlessly without receiving a response.

Final Reflection

I am doing everything I can to support my children: advocating, understanding their needs, following professional advice, and providing a safe, calm, neuro-affirming home. What I need is a system that recognises and supports that effort, rather than ignoring my requests.

I just want the right support — for them, and for me.

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