

# healthwatch

## Worcestershire

# Parent Carer Needs Assessment Report



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# Executive Summary

## Introduction

Healthwatch Worcestershire (HWW) is an independent organisation commissioned to champion health and social care across the county. Our reports share the experiences of local people, with decision-makers in the NHS and Worcestershire County Council to support the improvement of services.

*As part of this role, HWW received feedback from parent carers highlighting the difficulties they face when trying to access a Parent Carer Needs Assessment (PCNA). Many told us that even when they do manage to obtain an assessment, their own needs are often overlooked.*

The purpose of this report is to understand parent carers' experiences of requesting a PCNA from the Local Authority – to identify what is working well, where barriers exist, and how the process and support offered to families can be improved.

A total of 208 individuals responded to the online survey. Of these, 44 met the eligibility criteria of having requested a PCNA between January and December 2025. Among those eligible, 27 completed the full survey, and this report reflects the experiences of those individuals.

## Key Findings

1. There is a low awareness of the PCNA amongst parent carers.
2. The process of requesting a PCNA lacks ease and clarity.
3. There are multiple barriers to accessing a PCNA.
4. There is a general lack of communication around the PCNA.
5. Poor quality of PCNA for assessing needs and wellbeing of parent carers.
6. Those who completed the PCNA, the outcomes made little to no difference to the parent carer and their family.

## Conclusion

Survey findings highlight that those parent carers surveyed experienced weaknesses across the entire assessment process—from initial awareness to final outcomes.

Many of the parent carers were unaware of their legal right to request an assessment, indicating an information gap at the earliest stage. For those who do seek support, experiences are often characterised by unclear processes, long delays, and declined requests without transparent reasoning.

The findings suggest a need for clearer communication, consistent practice, better-qualified assessors, increased transparency, and a stronger link between assessment outcomes and meaningful support.

## Key Recommendations

- 1. Increase Awareness of PCNA Rights:** Share clear information through schools, health services, SEND teams, and digital platforms.
- 2. Simplify Request Process:** Provide a step-by-step guide and simple online request form for PCNA.
- 3. Improve Communication:** Give clear written timelines, next steps, and reasons for decisions to parent carers.
- 4. Provide Consistent Written Outcomes:** Use standard templates outlining needs of parent carer and next steps to access support.
- 5. Ensure All Key Needs of Parent Carers are Explored:** Use a structured framework in PCNA to include: wellbeing, respite, health, education/work, life outside caring.
- 6. Strengthen Link Between Assessment & Support:** Create clear pathways, collaborate with providers, and track follow-through.
- 7. Improve PCNA Assessor Training:** Provide training on disability, trauma-informed practice, and co-production.

# Background

## What is a Parent Carer Needs Assessment (PCNA)?

A PCNA is a statutory assessment carried out by local authorities for parents or guardians who care for a disabled child.

Its purpose is to understand the impact of the caring role on the parent, separately from the child's own assessment. It focuses on the parent carer's needs, circumstances, and wellbeing, helping to identify what support may enable them to continue caring in a safe and sustainable way.

The assessment recognises the parent as an individual in their own right, with their own needs and aspirations, and ensures these are considered alongside their caring responsibilities.

## What is the legal duty relating to PCNA?

Parent carers in England have a legal right to a PCNA under Section 97 of the Children and Families Act 2014, which adds sections 17ZD–17ZF to the Children Act 1989.

A parent carer is entitled to a PCNA if:

- The parent carer is 18 or over and has parental responsibility for a disabled child (as defined under Children Act 1989).
- They request an assessment or it appears to the local authority that they may need support.
- The child is someone the local authority can support under Section 17 of the Children Act 1989.

The local authority must carry out the assessment unless one has already been completed recently and circumstances have not changed.

### The assessment must consider:

1. The parent carer's wellbeing
2. Whether it is appropriate for them to continue caring
3. The need to safeguard and promote the welfare of the disabled child and any other children in the family

# Background cont.

## Why is it important for parent carers to have access to a PCNA?

Access to a PCNA is important because it ensures that the needs of the parent carer themselves are formally recognised. Parent carers often provide significant emotional, physical, and practical support, which can affect their own health, wellbeing, employment, and ability to manage daily life.

### A PCNA gives families a route to:

- Have their caring role acknowledged and understood.
- Identify unmet needs related to stress, health, or lack of respite.
- Access support or services that may reduce pressure on the family.
- Prevent carer burnout, which helps sustain their caring role.

Without access to a PCNA, parent carers risk being overlooked, unsupported, and left to manage complex caring responsibilities without guidance.

## What does a PCNA involve?

A Parent Carer Needs Assessment (PCNA) typically includes:

### 1. Understanding the Caring Role

- What the parent does day-to-day, level of care required.
- How caring affects the parent's routine and lifestyle.

### 2. Exploring the Parent's Needs

The assessment should cover key areas such as:

- Physical health and emotional wellbeing.
- Ability to work, study, or pursue goals.
- Access to respite.

### 3. Identifying Support Requirements

- Whether the parent needs practical, emotional, or financial support.
- Any services that could reduce strain or improve the wellbeing of a parent.
- Potential community or voluntary sector support options.

### 4. Agreeing Actions or Next Steps

- A written summary or support plan (where needs are identified).
- Information about available services, support routes, or signposting.
- Communication about timelines, decisions, and follow-up.

# Survey Methodology

The survey ran from 1 January to 31 January 2026. A full list of survey questions is provided in Appendix 1.

## Stage 1 – Reaching Parent Carers Across Worcestershire

The survey link was widely disseminated. A total of 208 parent carers living in Worcestershire took part in the initial survey.

## Stage 2 – Filtering To The Target Group

This report focuses on a specific subset of parent carers with following qualifying criteria:

- They requested a Parent Carer Needs Assessment (PCNA) since January 2025
- Their child/young person is under 16 years old
- Their child/young person is not supported by the Children with Disabilities Team

Out of the 208 respondents, 44 met all three criteria and were eligible to continue with the full survey.

## Stage 3 – Completion Of The Full Questionnaire

Of the 44 eligible parent carers, 27 went on to complete the remaining questions. The reasons why some eligible participants did not continue are unclear, as no follow-up information was available.

## Stage 4 – Case Study Participation

At the end of the survey, the 27 eligible participants were invited to take part in a more detailed case study interview: 9 parent carers expressed interest and 3 parent carers completed a full case study interview. The full case studies are included in Appendices 8,9,10, and shorter excerpts have been used throughout the report.

## Limitations Of The Survey

**Self-Reflection Bias:** Parent carers who completed the survey may be those with strong experiences, thus their views may not reflect the experiences across all parent carers.

**Eligibility Criteria Limitation:** Only a small number of parent carers met the eligibility criteria for completing the full survey. Hence, the findings represent the views of this specific group.

**Narrow Timeframe:** The survey captures the experiences for those who requested a PCNA between January to December 2025. Hence, the data reflects this period of activity.

**Anonymity Constraints:** To protect confidentiality, some contextual details in the survey and case studies were removed which reduces the level of detail available about individual circumstances.

# Survey Methodology

## Cont.

The primary survey method was an online questionnaire, with paper copies available for those who preferred not to use digital formats.

### **Promoting The PCNA 2026 Survey**

- An organic Facebook campaign (which consists of unpaid Facebook posts that promote the survey) were shared across HWW Facebook pages, shared with SEN parent carer Facebook support groups in Worcestershire, this helped circulate the survey organically through community networks.
- A paid Facebook advertising campaign was used to target parent carers more directly, ensuring the survey reached a wider and more diverse audience. Together, these approaches directed users straight to the same online questionnaire.
- The survey was also disseminated to Worcestershire schools, and Worcestershire County Council (WCC) disseminated it to all specialist SEN providers across Worcestershire.
- The survey was also promoted through the Healthwatch Worcestershire website and newsletter.

Parent carers could request assistance in completing the questionnaire if required. Parent carers were able to contact us to request: BSL interpretation, Easy Read materials, Large print versions or Translation services.

This approach ensured that parent carers had multiple, flexible ways to take part, helping us gather feedback from a broad range of families with differing needs, access requirements, and levels of digital confidence.

### **Demographics**

Demographic information was not collected as part of this survey.

# Key Findings

The questionnaire consisted of 28 questions: these have been listed in chronological order in Appendix 1.

In the following section respondents answers are grouped by themes, listed below.

Please note as you read through this section, the letter/number in brackets given alongside results refers to the relevant question in the survey.

## Categories

1. Awareness of the PCNA

2. Process of Requesting a PCNA

3. Barriers to Accessing a PCNA

4. Communication Around the PCNA

5. Quality of Assessment for Parent Carers

6. Outcomes for Parent Carers

# 1: Awareness Of The PCNA

## How aware are parent carers of their legal entitlement to a PCNA?

Full data tables and analysis are available in Appendix 2.

### Key Insight

Most parent carers surveyed were not aware that they have a legal right to request a PCNA, and those who did know, learned through informal routes rather than from professional services.

### Main Findings

- 75% of parent carers did not know they had a legal right to a PCNA. (Q1)
- Only 5% received the information via Social Care/Local Authority. (Q10)
- Half of those who were aware learned through informal routes such as; social media, other parents, or word of mouth. (Q10)

### What Parent Carers Told Us About Their Awareness of PCNA:

#### No Awareness of PCNA from WCC

"I only found out through this survey."

"Another parent told me. No professional ever mentioned it."

"Sendiass told me – not the council."

### What This Means For The Survey Participants

There is a major gap in statutory rights communication, and these families surveyed are largely relying on informal networks to discover their legal entitlements.

# Case Study

## Excerpt from Case Study One

### Learnt about PCNA via Facebook groups

#### Full version included in Appendix 8

*I work full time and I'm also a parent carer to three children, two of whom have complex needs and significant learning disabilities.*

*I didn't find out from any professional that I had a legal right to request a Parent Carer Needs Assessment – I only learned about it through other parent carers in Facebook groups. It felt strange to realise something so important was never communicated by the services that work with families like mine.*

*When I tried to request an assessment in summer 2025 because I was desperate for holiday childcare so I could keep working, the process immediately felt confusing.*

*The first question I was asked was whether I had family support before they even took my name, which felt judgemental. I chased the request seven weeks later only to be told there was no record of my call and all my information had been lost.*

# 2: The Process Of Requesting A PCNA

## How was the experience of requesting a PCNA for the parent carer?

*(Full data tables and detailed analysis are available in Appendix 23)*

### Key Insight

Parent carers found the process of requesting a PCNA difficult, unclear, and often unsuccessful. Many did not know they could request an assessment, and for those who tried, a substantial proportion either had their request declined or never received an assessment at all.

### Main Findings

#### Requesting a PCNA (Q3)

- Only 22% of respondents had a PCNA that actually went ahead.
- 26% had their request declined, with no clear explanation.
- 37% did not request an assessment simply because they did not know it was possible.
- 15% had “other” reasons for not progressing (e.g. being ignored, redirected, or losing confidence in the process).

#### Ease of Requesting a PCNA (Q11)

- 47% found the process difficult.
- Only 18% found it very easy, and 0% found it “somewhat easy”.
- Responses cluster at the difficult end of the scale, indicating poor accessibility and unclear pathways.

#### Time from Request to Completion (Q12)

- 71% reported the assessment was never carried out.
- Only 2 respondents said the process took 2–4 weeks.
- 3 respondents reported waiting over a month, in some cases as long as five months.

# 2: The Process Of Requesting A PCNA **Cont.**

## **What Parent Carers Told Us About The Process:**

### **Lack of follow up by WCC**

"I've been asking for a while and was told I'd be called back several times but haven't been contacted, so I've given up."

"I requested one but then chose not to go ahead in the end."

"We had an early help assessment instead."

"Currently waiting... months later."

"About 5 months."

These comments highlight unclear pathways, long delays, and inconsistent responses.

### **What This Means For The Survey Participants**

The process for requesting a PCNA is not well understood, not well communicated, and not consistently delivered.

A number of requests appear to be delayed or declined without a clear reason. Some parent carers, due to the process not working for them, said that they disengaged before an assessment was completed.

# Case Study

## Excerpt from Case Study One

### Why I Withdrew From The Process

#### Full version included in Appendix 8

*I spoke to other parents with similar needs and their experiences frightened me. I heard about processes that felt parent blaming, not child centred, and about reports that portrayed parents negatively for things outside their control. I realised that if I had 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.*

*Support locally is extremely limited, especially for children with higher needs. Activities and services are mostly designed for children with lower levels of disability and my children are often left with nothing appropriate. Only one holiday club in the whole area can take my children, and even if we (me and my partner) combine all our annual leave, we still end up short and have to take unpaid leave. Elderly relatives can't manage the children's needs, and working relatives aren't available – we are on our own.*

# 3: Barriers To Getting A PCNA

## What barriers do parent carers face when trying to access a PCNA?

(Full data tables and detailed analyses are available in Appendix 4)

### Key Insight

Parent carers reported multiple barriers that prevented them from accessing a Parent Carer Needs Assessment. The most common issues relate to not knowing about the assessment, not knowing how to request one, unclear processes, and poor communication, alongside long waiting times and emotional barriers such as fear of being judged.

### Main Findings

#### Barriers When Trying to Get an Assessment (Q4)

- 30% did not know they had a legal right to request a PCNA.
- 30% did not know how to request one.
- 26% said the process was unclear.
- 22% felt they were given insufficient information about the process.
- 22% experienced long waiting times.
- 19% were worried about being judged or misunderstood.
- 15% were told they were not eligible or were redirected elsewhere.
- 11% had their request declined without understanding why.
- 33% cited other barriers, indicating a wide range of additional issues.

#### Barriers During the Process (Q13)

Among the 15 respondents who answered:

- 47% said there was no clear information about next steps.
- 20% struggled to understand paperwork.
- 20% said communication from the assessor was unclear.
- 20% felt the assessment did not reflect their needs.
- 7% experienced language or communication barriers.

# 3: Barriers to Getting a PCNA Cont.

## **What Parent Carers Told Us About Barriers faced (Q14):**

### **Not knowing about PCNA**

*"I wasn't informed by the school that I could do this for my child."*

### **Not knowing how to request a PCNA**

*"Hard to know who to ask for the assessment."*

### **Lack of response from social services**

*"Request by email ignored by social services."*

*"I kept being told I'd get a call. I chased twice and still nothing."*

### **Negative and discouraging interactions**

*"I felt interrogated about why I wanted one."*

*"Was told it wouldn't involve a budget or respite – only signposting."*

*"Told my son wasn't 'disabled enough' to qualify."*

*"Waiting and not knowing what I'm waiting for."*

These quotes illustrate how unclear processes, inconsistent information, and a lack of communication can create significant barriers for families trying to access support.

### **What This Means For The Survey Participants**

Barriers to accessing a PCNA are systemic and wide-ranging, with most rooted in poor communication, lack of awareness, and unclear pathways. Many parent carers reported being redirected, ignored, or discouraged, which undermines trust and prevents families from receiving the assessment they are legally entitled to. Long waits and lack of follow-through further hinder access, leaving parent carers feeling unsupported and invisible.

# Case Study

## **Excerpt from Case Study Three**

### **Repeated Requests and Being Left Without an Assessment**

#### **Full version included in Appendix 8**

*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. I first made a written request for a Parent Carer Needs Assessment in late 2024.*

*Throughout early 2025, I repeatedly asked my social worker verbally for a Parent Carer Needs Assessment. 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.*

# 4: Communications

## How effectively is information about the PCNA communicated to parent carers?

(Full data tables and detailed analysis are available in Appendix 5.)

### Key Insight

Parent carers consistently reported poor communication throughout the PCNA process. No respondents felt that the process or next steps were explained clearly, and many described experiences of feeling dismissed, misunderstood, or judged. Communication issues significantly contributed to confusion, distress, and loss of trust in the system.

### Main Findings

#### What Parent Carers Told Us About Communication (Q27):

##### **Rude or abrupt initial contact**

*"The initial contact was quite rude... I still don't fully understand why I didn't qualify."*

##### **Minimising or misunderstanding needs**

*"My needs were minimised because my son has a mental disability, not a physical one."*

##### **Lack of understanding of disability and learning needs**

*"Nobody at WCC truly understands learning disabilities."*

*Communication: parents not feeling valued or prioritised*

*"Not being made to feel like a priority – I'm really struggling."*

##### **Fragmented services and inconsistent teams**

*"Why can't the team who already knows us do the assessment?"*

##### **Lack of response to emails or messages**

*"Emails weren't read or responded to."*

##### **Need for neurodiversity-focused training**

*"There needs to be neurodivergence training – urgently."*

These comments show clear gaps in empathy, disability understanding, and basic communication practice.

# 4: Communications **cont.**

## **Communicating the Process and Next Steps (Q17)**

- 0% of respondents said the assessor explained the process clearly
- 100% said the explanation of next steps was not clear

This is the strongest and most consistent finding across the entire survey.

## **What This Means For The Survey Participants**

Communication failures are widespread and significantly affect parent carers' experiences. Families are entering a legal assessment process without clear information, without feeling understood, and often without feeling respected. This creates confusion, reduces trust, and can discourage families from pursuing assessments they are legally entitled to. Communication weaknesses are a core driver of dissatisfaction across multiple survey categories.

# Case Study

## **Excerpt from Case Study Three**

### **Family Pressures, Burnout and What Would Make a Difference**

#### **Full version included in Appendix 6**

*Both my children have neurodivergent profiles and high levels of emotional distress. Supporting them requires constant awareness and a lot of emotional labour. In the past, I experienced a severe autistic burnout. I've worked extremely hard to recover, but the ongoing system stress makes it difficult.*

*If I could change one thing, it would be this: Parent Carer Needs Assessments should be carried out by professionals properly trained in neurodiversity, trauma, sensory processing, and family complexity. Parents shouldn't have to beg for support or chase endlessly without receiving a response. I just want the right support – for them, and for me.*

# 5: Quality Of Assessment

## What is the quality of the PCNA assessment experienced by parent carers?

(Full data tables and detailed analysis are available in Appendix 6).

### Key Insight

Parent carers reported consistently low quality in the assessments they received. Very few had their needs recognised, assessors were perceived as lacking understanding of disability and caring realities, and key areas of need were rarely explored. Written support plans—required to outline next steps—were almost never issued.

### Main Findings

#### Quality of Assessment In Terms of Recognition of Needs in the Final PCNA (Q5)

Among 27 respondents only six actually had a PCNA proceed:

- 0% said their needs were recognised in detail.
- Only 1 person reported their needs were recognised even vaguely.
- 30% did not receive a copy of their PCNA at all.
- 59% selected N/A, reflecting how few assessments were completed.

This suggests that even when assessments proceed, outcomes are unclear and inconsistently communicated.

#### Quality of Assessment in Terms of the Assessor Understanding of Disability and Caring (Q15)

- 43% strongly disagreed plus 15% disagreed that the assessor understood disability and caring challenges.
- 42% were neutral that the assessor understood
- 0% strongly agreed that the assessor understood

This indicates that assessments often lack empathy, specialist knowledge, and confidence in supporting complex caring situations.

# 5: Quality Of Assessment Cont.

## **Quality of Assessment in Terms of Areas Covered in the Assessment (Q16)**

Across 11–12 respondents per item, most reported that essential domains were not covered:

- 73–92% said key areas such as physical health, emotional wellbeing, respite, employment/education, and life outside caring were not discussed.
- Only one respondent indicated that area of employment/education was fully covered.

This suggests that assessments are not holistic and do not reflect statutory expectations under the Children and Families Act.

## **Quality of Assessment In Terms Of Identifying The Needs Of The Parent Carer (Q18)**

- 0% said their needs were clearly identified
- Only 1 said “vaguely”
- 13 said “No”

This shows that needs identification of parent carers—the core purpose of a PCNA—is not happening in practice.

## **Quality of Assessment In Terms of Receiving a Written Support Plan (Q19)**

- 0% received a written support plan
- 12 said no
- 1 was not sure

Written support plans are a critical part of recording agreed actions. Their absence indicates poor follow-through and lack of accountability.

# 5: Quality Of Assessment Cont.

## What Parent Carers Told Us About The Quality of Assessment:

### Assessment not completed

*"The assessment was left incomplete. I had to push for it, and then was told I needed a Child in Need assessment instead."*

### Lack of guidance

*"I wasn't given any guidance on what support was possible."*

### Lack of assessor knowledge

*"The assessor didn't seem to know what they were doing."*

### Needs not recognised

*"My needs weren't recognised at all."*

### Process perceived as pointless

*"They told me no one normally gets anything out of this."*

These examples show a system where assessments feel inconsistent, assessor knowledge varies, and expectations are poorly managed.

## What This Means For The Survey Participants

The quality of PCNAs reported by parent carers is consistently low and, in many cases, does not meet statutory requirements.

### Key concerns include:

- Poor understanding of disability, neurodiversity, and caring roles.
- Inconsistent or absent documentation (final reports and support plans).
- Lack of structured assessment tools, leading to important areas being overlooked.
- Weak identification of needs, meaning the assessment rarely leads to meaningful support.

Overall, the process lacks the rigour, clarity, and professional competency required to provide effective support to families.

# Case Study

## Excerpt from Case Study Two

**When the assessment finally happened, it was over the phone again – no home visit, no face-to-face meeting.**

**Full version included in Appendix 9**

*I'm a parent carer with several children who have additional needs, previously I have been awarded some wellbeing funding because of caring responsibilities for my older child.*

*Later on, in 2025, I tried to apply again, this time for support linked to my younger children. I contacted a local carers support charity. They booked me in for a phone appointment several weeks after my initial call.*

*Right from the start, the experience felt very different. 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.*

*When the assessment finally happened, it was over the phone again – no home visit, no face-to-face meeting. They asked the standard questions about my situation, income and circumstances. After the assessment, I was told I didn't qualify for any financial support this time.*

*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.*

# 6: Has The PCNA Made A Difference?

## What outcomes do parent carers experience as a result of the PCNA process?

(Full data tables and detailed analysis are available in Appendix 7.)

### Key Insight

For the parent carers who received (or attempted to receive) a Parent Carer Needs Assessment, the outcomes show little to no positive impact. Most saw no change, and some reported that the process made their situation harder. Satisfaction with the assessment process was very low, and almost no improvements were seen in wellbeing or family life.

### Main Findings

#### Outcome of the PCNA in terms of Impact on the Parent Carers, Caring Role (Q7)

- 4% said the PCNA made their caring role easier
- 4% said it helped “a little”
- 19% said it made no difference
- 4% said it made things harder
- 70% selected “Not applicable” (reflecting low numbers of completed PCNAs)

#### What This Means For The Survey Participants

Very few parent carers experienced any benefit, and for some the assessment introduced additional burden or stress.

#### Outcome In Terms Of Satisfaction With the Assessment Process (Q8)

- 48% were very dissatisfied
- 24% were somewhat dissatisfied
- 14% were neutral
- 0% were somewhat satisfied
- 14% were very satisfied

#### What This Means For The Survey Participants

72% expressed some level of dissatisfaction. Despite a small cluster of positive responses, the overall pattern indicates deep dissatisfaction, linked to communication issues, delays, and unclear outcomes.

# 6: Has The PCNA Made A Difference? cont.

## **Outcome In Terms Of Improvement In The Wellbeing Of The Parent Carer(Q22)**

From 12 respondents:

- 0 said their wellbeing improved
- 11 said no
- 1 was unsure

### **What This Means For The Survey Participants**

The PCNA did not contribute to improving parent carer wellbeing, its core statutory aim.

## **Outcome As Improvement For The Family Overall (Q23)**

From 12 respondents:

- 0% reported improvement
- 0% experienced "a little" improvement
- 75% said no difference
- 25% said it made things harder (e.g., increased workload, stress, unmet expectations)

### **What This Means For The Survey Participants**

The assessment process has no positive effect for families, and for some, it adds stress.

## **Positive Outcomes Experienced (Q24)**

From 5 respondents:

- 0% reported improved emotional wellbeing
- 0% better access to respite
- 0% less stress
- 0% improved family relationships
- 100% selected "Other"

### **What This Means For The Survey Participants**

Responses showing no positive changes and, in some cases, worsening circumstances.

## Outcome In Terms Of Improvement In The Wellbeing Of The Parent Carer(Q22)

### What Parent Carers Told Us About The Outcomes:

#### No Improvements

*"Things got harder because we felt let down."*

*"None – other than feeling unsupported by the very system that told me to apply."*

#### What This Means For The Survey Participants

Responses showing no positive changes and, in some cases, worsening circumstances. These insights show disappointment, and unmet expectations.

# Case Study

### Excerpt from Case Study Two

**The process didn't improve anything.**

**Full version included in Appendix 9**

*I am burnt out, overwhelmed and financially struggling.  
Everything feels like a battle.*

*Parent carers shouldn't have to hunt for information, chase assessments or figure out confusing processes. It would help to have a clear, consistent process, face-to-face assessments, proper explanations of what is available and decisions that feel fair.*

*Others in my yoga group had similar experiences – long waits, confusing information and very little support. None of us seemed to receive meaningful support. Being a parent carer is mentally, emotionally and financially challenging. The assessment process didn't help and reinforced how hard it is to access the help we're legally entitled to. All I want is a system that understands the reality we live in.*

# Conclusion

Taken together, these findings suggest that the issues identified are not isolated operational problems but reflect broader systemic weaknesses in the design and delivery of the Parent Carer Needs Assessment (PCNA) process.

Across areas of awareness, access, communication, quality, and outcomes, parent carers describe a pathway that is difficult to navigate, inconsistently implemented, and rarely results in meaningful support.

The data indicates a disconnect between the statutory intention of the PCNA and the lived experiences of parent carers.

While the assessment is intended to recognise parent carers as individuals with their own needs, many respondents reported feeling invisible, unheard, or discouraged from engaging with the process.

Communication challenges appear to underpin many of the difficulties identified, contributing to confusion, mistrust, and disengagement.

Even where assessments were completed, they frequently lacked a holistic exploration of wellbeing, clear documentation, and meaningful follow-up, limiting their overall impact.

These findings suggest that improvements are needed not only at the point of assessment but across the wider system that supports it, including information sharing, professional training, accountability mechanisms, and stronger links to support services.

The recommendations that follow are therefore aimed at strengthening the PCNA pathway as a whole, ensuring that it operates transparently and consistently, and that it fulfils its statutory purpose of supporting parent carers and safeguarding family wellbeing.

# Recommendations

## 1. Independent Audit of PCNA Practice

- Commission an independent audit of the PCNA process to assess compliance with statutory duties, identify gaps, and ensure the service operates in line with legal requirements and best practice.
- Working in partnership with parent carers to co-produce PCNA process and establish best practice.

## 2. Mandatory Reporting and Data Transparency

Introduce mandatory public reporting on PCNA activity, including:

- number of assessments requested
- number completed
- number declined
- reasons for decline
- average waiting times

Regular reporting will strengthen accountability and support service planning.

## 3. Improve Awareness of the Legal Right to a PCNA

Increase awareness of the PCNA by:

- providing clear, accessible information on eligibility and entitlements
- promoting PCNAs through schools, GPs, health visitors, SEND services, family hubs, and community organisations
- using social media and short explainer content to reach wider audiences

Ensure parent carers know they have a legal right to request a PCNA at any time.

## 4. Automatically Offer PCNAs at Key Transition Points

Proactively offer a PCNA at significant points in a child or family's journey, such as:

- when an EHCP is issued or reviewed
- during key transitions (school moves, diagnosis stages, significant changes in care needs)

This reduces reliance on parent carers discovering their entitlement themselves.

## 5. Simplify and Clarify the Request Process

- Create a clear, step-by-step guide on how to request a PCNA
- Introduce a simple online request form and confirmation process
- Ensure all frontline professionals understand how to support parents to request an assessment

This will remove confusion and increase accessibility.

## 6. Separate the Supportive PCNA Pathway from Safeguarding Roles

- Establish a clear structural and communication separation between PCNA assessments and safeguarding functions.
- Clear messaging is essential to reduce parent carers' fear of social care involvement acting as a barrier to requesting support.

## 7. Introduce a Formal Right to Appeal PCNA Decisions

Develop a transparent appeals process that includes:

- a formal written decline letter
- clear explanation for decisions
- information on the right to appeal
- a named contact for review

This ensures fairness and procedural clarity.

# Recommendations cont.

## 8. Strengthen Communication Throughout the Assessment Journey

- Provide clear explanations of next steps, timelines, and what the process involves
- Ensure assessors communicate outcomes and decline reasons consistently
- Use a communication checklist to improve consistency

## 9. Reduce Waiting Times and Improve Completion Rates

- Review current workflows and identify bottlenecks
- Implement monitoring to ensure assessments are completed within expected timescales
- Increase capacity or redesign processes to reduce “never carried out” cases

## 10. Improve the Quality and Consistency of Assessment

Introduce a structured assessment framework to ensure all key domains are covered, including:

- physical health
- emotional wellbeing
- education/work
- respite
- life outside caring

Audit completed assessments to ensure these domains are addressed.

## 11. Improve Assessor Training and Professional Confidence

Provide enhanced training that goes beyond basic disability awareness, including:

- complex disability understanding
- carer challenges
- co-production and empathy
- trauma-informed communication
- neurodiversity and sensory needs

Include reflective supervision to maintain quality.

## 12. Ensure Written Outcomes Are Consistent and Clear

Make written reports and support plans mandatory wherever needs are identified, ensuring they include:

- clear actions
- timescales
- responsible teams

Share documents with families and relevant professionals (with consent).

## 13. Strengthen the Link Between Assessment and Support

- Build clear pathways from assessment outcomes to actual support services
- Improve join-up between services
- Use case-tracking to ensure that agreed actions are followed through

## 14. Enhance Emotional Safety and Reduce Stigma

- Reassure families that PCNAs are supportive, not judgemental
- Use consistent, sensitive language that clearly separates assessment from safeguarding

Promote a culture of empathy and respect

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This report has been reviewed using digital tools to support accuracy and clarity. Please note that AI was not used in the collection of data.

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