Report of Experiences of Parent Carers of Disabled Children and Adults Across Wales

Executive Briefing for Ministers, Local Authorities, and Health Boards

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Preface: Background of this Report

Firstly, sincere thanks are extended to the 112 parent carers who took the time to complete this survey and share their experiences. Their willingness to contribute has enabled this report to be developed at a time when growing research and public discussion highlight the need for meaningful change within systems that support disabled children, adults, and their families.

The purpose of this survey is to raise awareness of the experiences of parent carers across Wales and to highlight areas where improvement and reform may be needed. Recent research, including work by Professor Luke Clements and Ana Aiello of Leeds University in partnership with the Cerebra charity, has identified concerns around parent-carer blame and the wider impact of systemic responses to families seeking support. Publications such as *Understanding Parent Blame: Institutional Failure and Complex Trauma* (2025), alongside reports from WMADASS and the Challenging Behaviour Foundation, have echoed similar themes.

Research and lived experience suggest that some families encounter systems that apply standardised approaches to highly complex situations. Parents have described feeling blamed or dismissed when advocating for appropriate support, and some report experiences that contribute to distress, mistrust, or what has been described as “systems-generated trauma”. These issues have prompted increasing calls for greater transparency, collaboration, and co-production between families and statutory services.

This survey was developed from both professional and personal perspectives. As a parent carer with lived experience of navigating education, health, and social care systems, and through many years of involvement in voluntary work, research, and professional collaboration, the aim has been to contribute constructively to conversations about how systems can improve. Many families continue to advocate for their loved ones while managing significant personal challenges, and some feel unable to speak openly due to ongoing legal or professional pressures.

It is hoped that this report helps to provide context for why the survey was undertaken and why raising awareness of these experiences is important. The findings that follow reflect the voices of families who wish to see systems evolve in ways that are more transparent, supportive, and responsive to individual needs.

Clare Lucignoli

1. Purpose of this report

This report summarises findings from a parent-led survey examining the experiences of parents and carers of disabled children and adults when seeking support from local authorities, health boards, education services, and commissioned care providers.

The aim is to identify recurring patterns within statutory systems that contribute to harm, distress, and unmet need among families, and to highlight areas where change is required.

The findings are intended to inform Welsh Government ministers, local authority leadership, health boards, and cross-party groups with an interest in disability, health, and social justice, and to support decisions about future policy and practice.

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2. Background and rationale

The survey was developed in response to increasing concern among parent carers about the way statutory systems operate when families request support.

These concerns include growing academic and professional attention to parent-carer blame, documented use of safeguarding and FII-related practices in disability contexts, and media reporting of systemic failures across education, health, and social care services.

Alongside this, many parent carers reported similar lived experiences of fear, mistrust, and harm when engaging with statutory services.

A questionnaire approach was chosen to allow both numerical trends and detailed lived experience to be captured, while enabling anonymity due to widespread concern about possible repercussions. The intention was to understand whether these experiences reflected broader, repeatable patterns across families and services.

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3. Respondents and scope

The survey received 112 responses from parent carers[1].

Respondents cared for children and young adults with a wide range of disabilities, frequently involving multiple and complex needs. The ages of those cared for ranged from early childhood into adulthood. Most children lived at home, with parents providing significant levels of unpaid care alongside interactions with education, health, and social care services.

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[1] A small number of earlier responses from an initial version of the questionnaire were incorporated into the final dataset where question wording aligned.

The survey reflects experiences across a broad parent-carer population rather than a single diagnostic group or service pathway.

4. Headline findings from 112 parent carers

The following headline figures summarise the most consistent and significant patterns identified across the survey responses:

- **86%** of parent carers reported that supporting their disabled child or adult had negatively affected their physical or mental health.
- **44%** of parent carers reported having a long-term physical or mental health condition.
- **84%** of respondents stated that their child was not receiving an appropriate level of support.
- **Only 17%** of parents believed the right support was currently in place for their child.
- **Over 50%** of respondents reported experiences of parent-carer blame by statutory agencies.
- **25%** of families reported receiving no funded support despite caring for children with complex needs.
- **84%** of those who used formal complaints processes said their complaint did not resolve the issue raised.
- Fear of retaliation, including escalation to safeguarding processes or loss of support, was repeatedly cited as a reason for not requesting help.

These findings are supported by both quantitative responses and consistent qualitative testimony throughout the dataset. Percentages reflect the final dataset of 112 respondents.

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5. Key findings

5.1 Impact on parent carers' health and wellbeing

A large majority of respondents reported negative impacts on their physical and mental health linked to supporting their child.

Parents described chronic stress, anxiety, depression, trauma-related symptoms, physical injury, sleep deprivation, and financial strain. Many reported leaving employment or reducing working hours in order to meet care needs. These impacts accumulated over time and were frequently linked to interactions with statutory services rather than to caring alone.

5.2 Insufficient and delayed support

Most respondents reported that the support available to their child did not meet their needs.

Parents described long waits for assessments, lack of coordinated multi-agency input, poor communication between services, and support being offered only once families reached crisis point. Children with complex needs were frequently described as receiving fragmented or inadequate care across education, health, and social care.

5.3 Use of parent-carer blame

A recurring theme throughout responses was the experience of being blamed or disbelieved when seeking support.

Parents described being held responsible for their child’s distress or unmet needs, having professional judgments override lived expertise, and facing questioning of parenting capacity. Some reported safeguarding or FII-related processes arising following requests for support. These experiences contributed to distress, withdrawal from engagement, and long-term mistrust of services.

5.4 Fear as a barrier to accessing support

Fear emerged as a significant factor influencing whether parents felt able to ask for help.

Respondents described concerns about escalation to safeguarding procedures, loss of existing support, or placement of their child outside the family home. Some reported that fear prevented them from raising concerns, making complaints, or sharing their experiences openly. This reduced access to support and increased isolation.

5.5 Complaints systems and accountability

A minority of respondents had used formal complaints processes. Among those who had, most reported that their complaints did not lead to meaningful resolution.

Complaints were frequently described as inaccessible, emotionally exhausting, and managed by the same organisations responsible for the original concerns. Parents described defensive responses, lack of transparency, and deterioration in relationships with services following complaints.

5.6 Allocation of resources

Parents described repeated refusals of funding for frontline care alongside extensive use of legal processes, case management, and adversarial approaches.

Families reported prolonged disputes involving legal representation and significant associated costs, both for themselves and for public bodies. These experiences raised concerns about whether resources are being used in ways that prioritise effective support, prevention, and long-term outcomes.

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6. Overall interpretation

Taken together, the findings indicate persistent patterns across education, health, and social care systems that contribute to harm for families with disabled children and adults.

Parents described services that are difficult to navigate, slow to respond, and experienced as adversarial. The cumulative impact includes deteriorating health for carers, unmet needs for children, reduced trust in statutory services, and increasing long-term social and financial costs.

7. Priority actions arising from the findings

Action 1: Address parent-carer blame within statutory processes

Clear safeguards are required to prevent parent-carer blame from being embedded within assessment, safeguarding, and care planning processes. Safeguarding and FII-related approaches should be applied only where evidence thresholds are clearly met, with appropriate oversight and transparency. Parents' lived knowledge of their children should be recognised within professional decision-making.

Action 2: Strengthen complaints and accountability mechanisms

Complaints systems require reform to ensure independence, accessibility, and trauma-aware practice. Processes should enable parents to raise concerns without fear of negative consequences, and should lead to clear remedial action when failings are identified.

Action 3: Improve co-production and transparency in decision-making

Families should be meaningfully involved in assessments, care planning, and reviews. Decision-making criteria and funding rationales should be clearly explained, and refusals of support should be accompanied by transparent reasoning and information about routes for review or appeal.

Action 4: Invest in early and preventative support

Greater emphasis on early intervention, coordinated care, and respite support would reduce crisis-driven responses and long-term harm. Supporting parent carers' wellbeing contributes to improved outcomes for children and more sustainable use of public resources.

8. Implications for decision-makers

The evidence presented highlights the need for system-level change to ensure that statutory services are experienced by families as safe, fair, and responsive.

Addressing the issues identified would improve trust, reduce avoidable harm, and support better outcomes for disabled children and adults, their families, and the public services that support them.

Closing Note

This report represents the voices and experiences of 112 parent carers across Wales who chose to share their perspectives in the hope that positive change can follow. The findings are intended to support ongoing discussion, reflection, and collaboration between families, practitioners, and decision-makers.

It is recognised that this survey reflects lived experience at a particular moment in time. Continued engagement, further research, and open dialogue will be important in shaping future developments that better support disabled children, adults, and their families.

Readers are encouraged to consider the findings within the context of wider Welsh and UK research on co-production, carers’ rights, and system accountability. The intention is not only to highlight challenges, but to contribute constructively to future solutions.