



Carer's Needs Assessment Survey 2019

This is a report from a survey that collected parent carers' knowledge and experiences of Carer's Needs Assessment in the City and County of Swansea since 6th April 2016. The survey ran from 26th October 2019 to 10th December 2019 and was completed by 212 parent carers. Of those who took the survey, 193 indicated they lived in Swansea and the analysis in this survey is based on the responses of those parent carers.

Background

The Welsh Government's vision for carers in Wales is one where all carers are identified, recognised and supported for the invaluable care and commitment they provide.

The Social Services and Well-being (Wales) Act 2014 gave carers the same right to have their needs assessed as those they care for and under the Act, carers are entitled to an assessment regardless of the amount or type of care provided, financial means, or level of support needed. The 3 Welsh Government's national priorities for carers are:

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

About the survey

The survey was developed by Swansea Parent Carer Forum (SPCF) in collaboration with officers from Swansea Council and Swansea Carers Centre. It was an online survey and distributed to the main parent carer forums who use private Facebook groups in Swansea. The survey was also shared and publicised by Swansea Carers Centre, Swansea Council for Voluntary Services (SCVS), Swansea Parent Carer Forum (SPCF), Swansea Council and others across their social media channels and e-mail distribution lists.

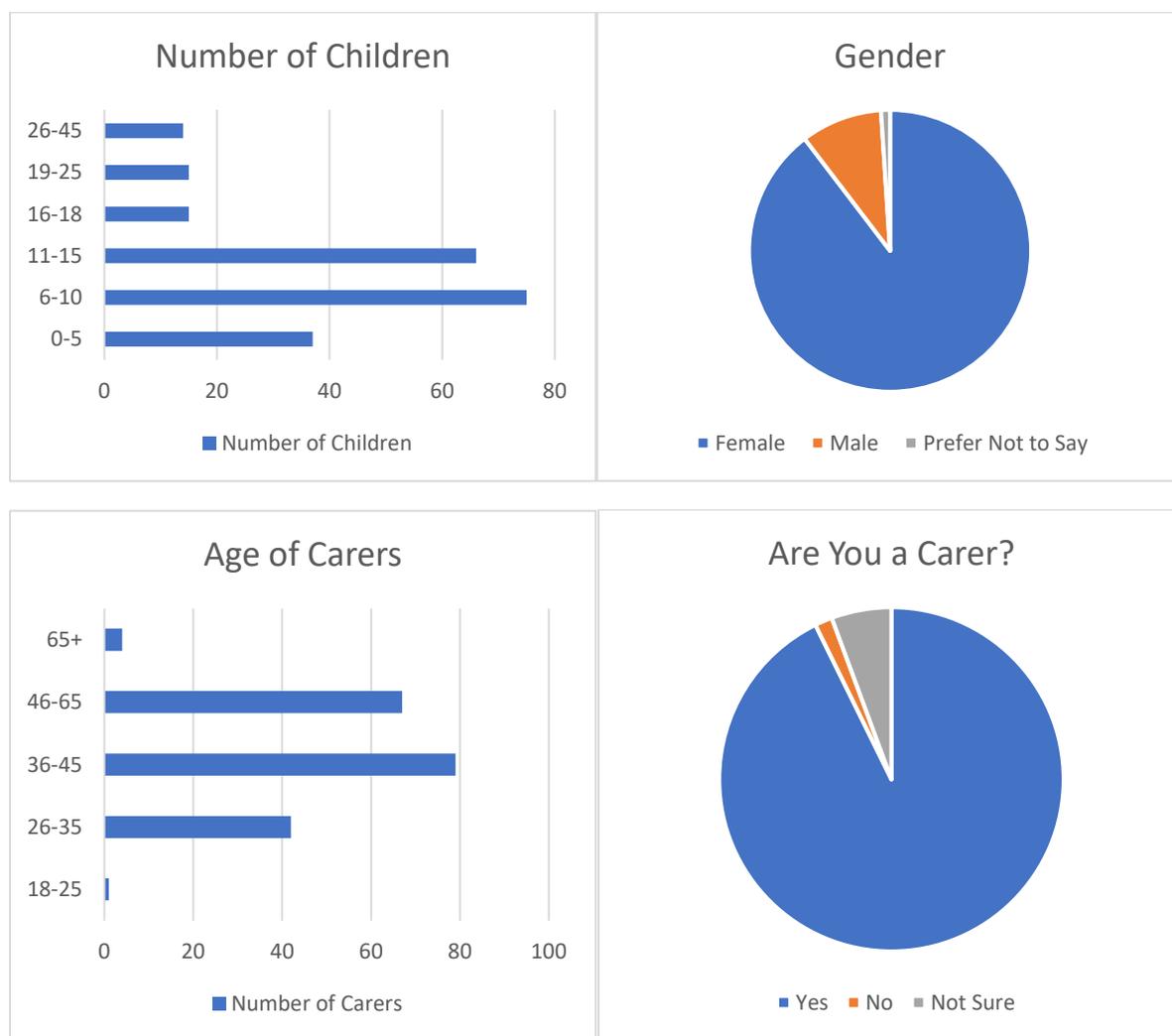
Some specific social media posts encouraged male parent carers to participate in the survey. Parent carers were encouraged to take the survey regardless of their knowledge of assessments or engagement with statutory services.

During this period there were opportunities to reach parent carers not engaged online at a Carer’s Rights Day hosted by Swansea Carers Centre and a LA scrutiny session also hosted by Swansea Carers Centre. SPCF hosted a workshop by Cerebra where the survey was highlighted to parent carers as well as during other informal contact with parent carers.

Typically Facebook ‘closed’ parent carer support groups around 600 members. A response of 193 should give confidence on the data’s reliability.

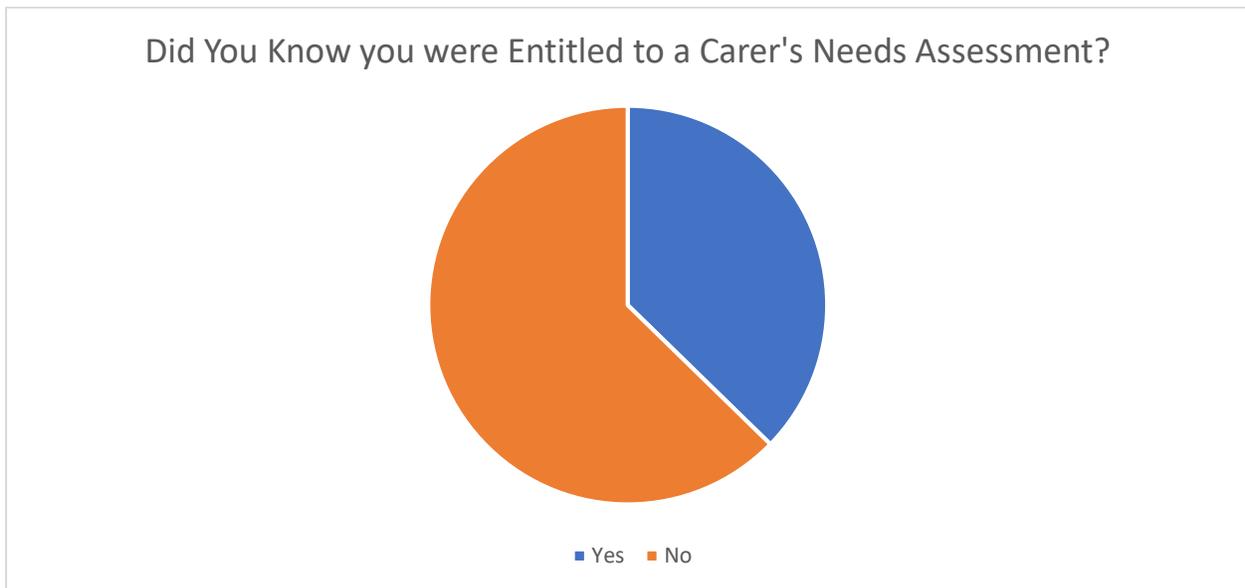
Overview of Survey Participants

The Parent Carers who participated in the survey had children covering a broad range of ages. 81% of those surveyed were female reflecting the well documented caring roles primarily falling to women and male carers not necessarily identifying as carers. Most participants identified themselves as carers with 5% unsure or did not. No analysis has been performed based on demographics.



Who knows about Carer's Needs Assessments

1 in 3 parent carers said that they were aware of their right to a Carer's Needs Assessment. Examining which services and agencies parent carers engaged with social services and the 3rd sector where more aware of their right to a Carer's Needs assessment. Both groups had similar high proportion of children with Statements of Educational Need (so engaged in a statutory service) which suggests this may be a good route to inform carers. In hindsight, an explicit question around how they knew about Carer's Needs Assessments might have been useful. There are clearly opportunities to better inform parent carers of their rights by statutory services, agencies and the third sector with both education and GPs being universal services. Although all carers are likely to be registered with a GP, only 1 in 5 parent carers are registered with them as a carer, potentially missing opportunities to support their health and wellbeing.



	Whole group (193)	Knew (72)	Didn't know (121)
Social Services	89 (46%)	50 (69%)	39 (32%)
Registered with GP	43 (22%)	24 (33%)	19 (15%)
Child with SEN*	143 (74%)	52 (72%)	91 (75%)
Referred to TAF /CAMHS**	69 (36%)	30 (43%)	39 (32%)
Engaged with 3 rd Sector	105 (54%)	51 (71%)	54 (45%)

*Statement of Educational Need

**Team Around the Family/Child Adolescent Mental Health Services

“My child is on the Swansea register for disabled children, so you'd think I'd have been told about the carers assessment”

“It would have been beneficial that such information was given once a child is given a statement of special needs.”

“I have been told about Carer's Center only about a year ago, and since then I have been given so much help and advice on many things that I could not even begin to imagine. I am very grateful to the nurse at Singleton Hospital who suggested to me Carer's Center almost a year ago. Now I have support I couldn't even dream of... Life is still a roller coaster but at least I have someone to ask for help.”

There were no particular difference in engagement to services if a parent carer was not in contact with Social Services.

Carer's Needs Assessments

The second part of the survey looked at those carers who may have had a Carer's Needs Assessment; offered an assessment or asked for one. The Social Services and Wellbeing Act 2014, requires a local council to offer a Carer's Needs Assessment as soon as it appears there may be needs for support. Previously a carer needed to ask for an assessment.

Less than 1 in 10 parent carers surveyed have been **offered** a Carer's Needs Assessment and almost 1.5 in 10 have **asked** for one. 'Not knowing' of its existence or assuming they were 'not entitled' were the leading reasons parent carers gave why they had **never asked**.

Since 6th April 2016, have you been OFFERED a Carer's Needs Assessment?

No	176	91%
Yes	17	9%

Since 6th April 2016, have you ASKED for a Carer's Needs Assessment?

No	150	86%
Yes	25	14%

Why have you never asked for a carer's needs assessment? (Participants able to select as many that applied.)

I am overwhelmed at the prospect of another assessment	19
I don't need one	11
I've heard the process is very invasive	14
I've heard nothing happens even if you have identified needs	14
I am reluctant to let social services into our lives	25
I didn't know they existed	85
I've not been offered one so assume I'm not entitled	55

'I'm not sure I would be entitled as I can't find anything that describes entitlement in a meaningful way for me. I'm not likely to put myself through an assessment if I'm not confident that something will come from it. I think I do have needs but I will automatically live with those as long as my child's needs are met. This may not be the best thing in the long term.'

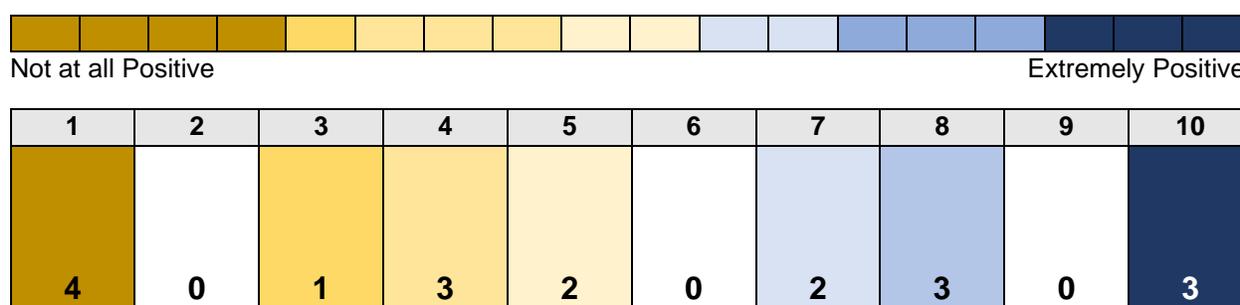
Parent Carers Who Were Offered an Assessment

18 of 193 participants have been offered a Carer’s Needs Assessment.

The Assessment

All were already in contact with Social Services and were predominantly offered an assessment by their child’s social worker when their child’s needs were FIRST assessed or were being formally reviewed. More than half reported an assessment date was arranged with two weeks. All assessments took place at the recipient’s home with a third being conducted during a joint review with their child and a third unsure if this was the case.

We asked these participants to scale their experience of an assessment from 1 (not at all positive) to 10 (extremely positive). Experiences were mixed with a third of participants not experiencing a positive experience.



“Felt like they did not believe how poorly I was doing a caring role for 2 people.”

“Excellent, the lady who came was very empathetic”

“It actually highlighted my child was experiencing other difficulties”

The Outcomes

Most reported that ‘needs’ were identified through their Carer’s Needs Assessment, although some were unsure. Those that were unsure went on to indicate they weren’t aware if a ‘Care and Support Plan’ had been completed and had never received a copy.

Support Offered

Parent Carers reported a range of support offers; direct payments, childcare, transport, signposting, day provision and respite. Most but not all received their offer of support.

Parent Carers Who Asked for an Assessment

25 people told us that **they have asked** for a Carer’s Needs Assessment since April 2016. They appear to have a markedly different experience than those who were offered an assessment.

The Assessment

Carers asked for an assessment by contacting the Child and Family Information, Advice and Assistance Service (8 in total) or asking their child’s social worker (16). They described delays and having to persistently chase up their request. Others described being refused or signposted elsewhere.

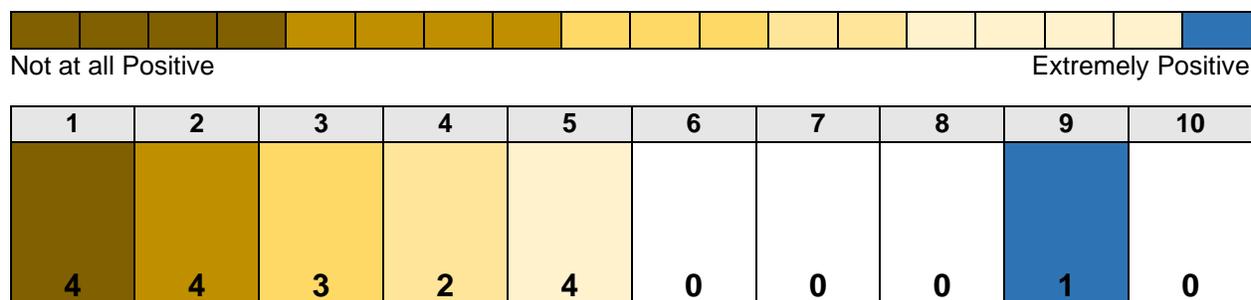
“Had to chase up several times.”

“Had to keep asking and put in a formal complaint before I got one.”

“I was repeatedly fobbed until they caved in”

Subsequently, most report long delays in arranging an assessment with most reporting it took more than 4 weeks to arrange the assessment. All assessments took place at the carer’s home. Two carers said that only a core assessment took place.

Very few of these carers had a positive experience with only one carer scoring higher than 5.



The Outcomes

No carers were aware of a ‘Care and Support Plan’ being completed and none received one. Few were able to identify any support offered although needs were identified. They were asked on a scale of 1 to 10 if the support they received. Most felt their needs were not met at all.

“It was stressful, cold, there was no established relationship, I had prepared very well but the social worker did not have the appropriate background to conduct the assessment.”

“The assessment was not interested in my needs”

“Intrusive”

“I have had an awful experience of social services and how hard it has been just to be accepted for the carers assessment.....I was crying out for help to keep my family together and I was still denied the assessment for 18-24 months before finally being accepted on to the list for a carers assessment.”

“Social workers just talk about my 'child' .not my needs.”

“It was a collaborative approach, where I felt I had voice and control over my information and shaped with the support of my caseworker.”

There was a notable contrast compared to parent carers who were offered an assessment and most parent carers who asked for an assessment said that their needs had not been met.

Advice and Information

We asked parent carers if they received any advice or information. Few participants responded to this question and were advised of other 3rd sector organisations and to register with their GP. Some indicated this information was useful.

“Told we were a complex family, nothing available for us so case closed.”

“Where I could take my prospective autistic child to socialise and what venues we could attend that would be suitable for him and his little brother.”

“I was told I had to register with my GP as they don't do assessments.”

Signposting

We asked parent carers about any signposting to other organisation and services and if this was useful. Very few participants answered this question. They reported they were signposted to Evolve, Diversity, Swansea Carer’s Centre and Integrated Autism Service. Most accessed the service they were signposted to. All reported that these referrals did not meet their needs.

Disability Living Allowance

12 parent carers state they have been advised to use their child’s Disability Living Allowance (DLA) to help them meet their caring needs. It would be useful to clarify the role DLA should or should not play in supporting needs of parent carers to fulfil their caring role. DLA is meant to cover the extra costs incurred by disabled children.

Complex Cases

Although not covered specifically in this survey one family reported that they had never received support from social services as their child receives CYP Continuing Care from the NHS.

“My 'child' is 100% health care funded so social services don't have any input after 18 years!”

Although CYP Continuing Care does not negate a local council from meeting any social care, Carer's Needs Assessments should consider how it meets the needs of parent carers of children and young people with complex needs. Assessments can sometimes be carried out jointly with another agency, such as the NHS, to ensure that all the professionals involved in a person's care are talking to each other when decisions about care are being made. We should consider this in the context of meeting the needs of parent carers who have a child with particularly complex needs.

“If a child or young person is found to be eligible for children and young people's continuing care (CYP CC,) the LHB is not the responsible body for funding any social care which may be needed - this remains a LA responsibility. A LHB and a LA may therefore jointly fund care to meet a child or young person's needs – as part of a joint health and social care package.” Welsh Government Consultation Document – CYP People's Continuing Care 17 May 2019.

Seldom Heard Voices

This survey was unlikely to reach families where English was not a first language and other seldom heard groups. One parent carer highlighted the isolation and difficulty they experienced accessing information just because they worked full time.

“My husband and I care for our autistic 'child' and work fulltime. We feel incredibly isolated from all carer events due to this main fact. We miss out on much needed information and connections with other parents. “

Consideration should be given to seldom heard voices as Carer's Needs Assessments are developed in Swansea as well as the spectrum of support

What would help?

The survey asked if anything would have helped further. The comments suggest Carer's Needs Assessment would benefit from being part of a process where good relationships are developed and the output of assessments co-produced encompassing the needs of both the cared for and the carer.

“A better knowledge of the system and also for the social workers to understand the system better. “

“Follow up conversation, annual carer assessment as needs change”

“Properly coproducing the assessment. Issues raised have not been addressed. Disagree with the support identified as(.apart from referral to respite) it does not actually help address the issues. Still working to try to resolve this but LA very slow responding. Has been outstanding since July 2018.”

“Better assessment process, building relationships with parents, once needs are identified, delivery the appropriate support.”

“Being accepted for the assessment when I initially asked for one, rather than being fobbed off with the needs assessment they were doing would cover the same things. “

“Continuity with social worker would have been helpful, original one left, 2nd one filling in left, 3rd one gave me a trainee who was good & then left..... All very long winded and restbite provision have to liase with me & social worker which is fine if you have a good social worker.....”

“A structured assessment that actually encapsulated the full picture. We had a genetic diagnosis at the start if this and now we are going through asd diagnosis. Therefore our circumstances are different.”

“Paperwork completed and sent back to us in timely manner identifying our care plan and more autonomy to manage the respite side and enable my mother to receive direct payments to help us as all other forms of respite fell through and the person working with... paid by DP is frequently off sick or on holiday and we have no replacement when she’s not here. Recruiting is extremely difficult. The bureaucracy of everything is time-consuming and bewildering.”

About Swansea Parent Carer Forum

Swansea Parent Carer Forum are a voluntary group of parent carers all with children with additional needs. We work with but are independent of the City & County of Swansea, our aim being, to make sure that services meet the needs of disabled children, young people, adults and their families. We believe passionately that working co-productively with Swansea Council and other service providers will put the voice of disabled children of all ages and their families at the centre of decisions and deliver services that work for our community.

The Forum has been working with Swansea local authority on a task and finish group to explore the issues being reported about carer's assessments by its parent carer membership.

The aim of the group is to:

- explore the experiences of local families and the barriers to gaining assessments and the support they require.
- identify and implement ways in which carer's assessments are carried out and reviewed.
- explore ways in which the identified needs can be addressed and supported.
- explore how child and family services, adult services and the third sector can work together to ensure a seamless service.
- develop and publicise local information about carer's assessments and pathways to gaining access to them.

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