



AWARENESS OF THE CARERS (SCOTLAND) ACT

Experiences of Carers in Scotland

January 2019

Table of Contents

(1)	INTRODUCTION	2
(2)	WHO RESPONDED TO THE SURVEY?	3
(3)	ARE CARERS AWARE OF THE CARERS (SCOTLAND) ACT?.....	5
(4)	ARE CARERS AWARE OF THEIR RIGHTS WITHIN THE CARERS ACT?	7
	THE RIGHT TO BE INVOLVED IN PLANNING OF CARER SERVICES	8
	THE RIGHT TO BE INVOLVED IN THE HOSPITAL DISCHARGE PLANNING OF THE PERSON THAT YOU ARE CARING FOR	9
	THE RIGHT TO TAKE CARERS' VIEWS INTO ACCOUNT WHEN ASSESSING THE NEEDS OF THE PERSON BEING CARED FOR	10
	THE RIGHT TO BE INVOLVED IN THE ASSESSMENT OF THEIR OWN NEED FOR SUPPORT	12
	THE RIGHT TO ACCESS SUPPORT IF A CARER MEETS THE LOCAL ELIGIBILITY CRITERIA.	14
	THE RIGHT TO ACCESS A YOUNG CARERS STATEMENT IF YOU ARE A YOUNG CARER.....	16
	THE RIGHT TO ACCESS AN ADULT CARER SUPPORT PLAN IF YOU ARE AN ADULT CARER.....	18
	THE RIGHT TO RECEIVE INFORMATION AND ADVICE, INCLUDING INFORMATION ABOUT YOUR RIGHTS AS A CARER.	20
(5)	KEY RECOMMENDATIONS.....	23
	RECOMMENDATION 1: RESOURCES TO IMPLEMENT THE CARERS (SCOTLAND) ACT	23
	RECOMMENDATION 2 : BETTER AWARENESS FOR HEALTH, SOCIAL CARE, AND EDUCATION STAFF	24
	RECOMMENDATION 3: RECOGNISING THAT CARERS AND CARED FOR PEOPLE HAVE DIVERSE SUPPORT NEEDS	25
	RECOMMENDATION 4: IMPROVE ACCESS TO INFORMATION AND ADVICE FOR ALL CARERS	26

(1) Introduction

- In November 2018, the Coalition of Carers in Scotland (COCIS) developed a short survey to find out whether unpaid carers in Scotland were aware of the Carers (Scotland) Act and of the enhanced and extended rights within the new legislation.
- A link to the survey was shared with all of the local Carers Centres in Scotland as well shared on the COCIS social media channels.
- The survey was live from 7 Nov – 28 Nov 2018 and received responses from 1035 carers from across Scotland.
- This paper provides a summary of the responses to the survey questions and an analysis of the comments from the carers.
- Not all the respondents completed every question in the survey, so we will include the sample size for each of the questions when reporting on the individual findings.
- We also need to acknowledge that the carers who did respond to the survey would have been those who were able to readily access the online survey. We were not able to offer an alternative to the online survey on this occasion, so this may have excluded carers who live in areas where internet connectivity is an issue; or who are not confident in using technology; or who have issues with literacy or unable to understand English.

(2) Who Responded to the Survey?

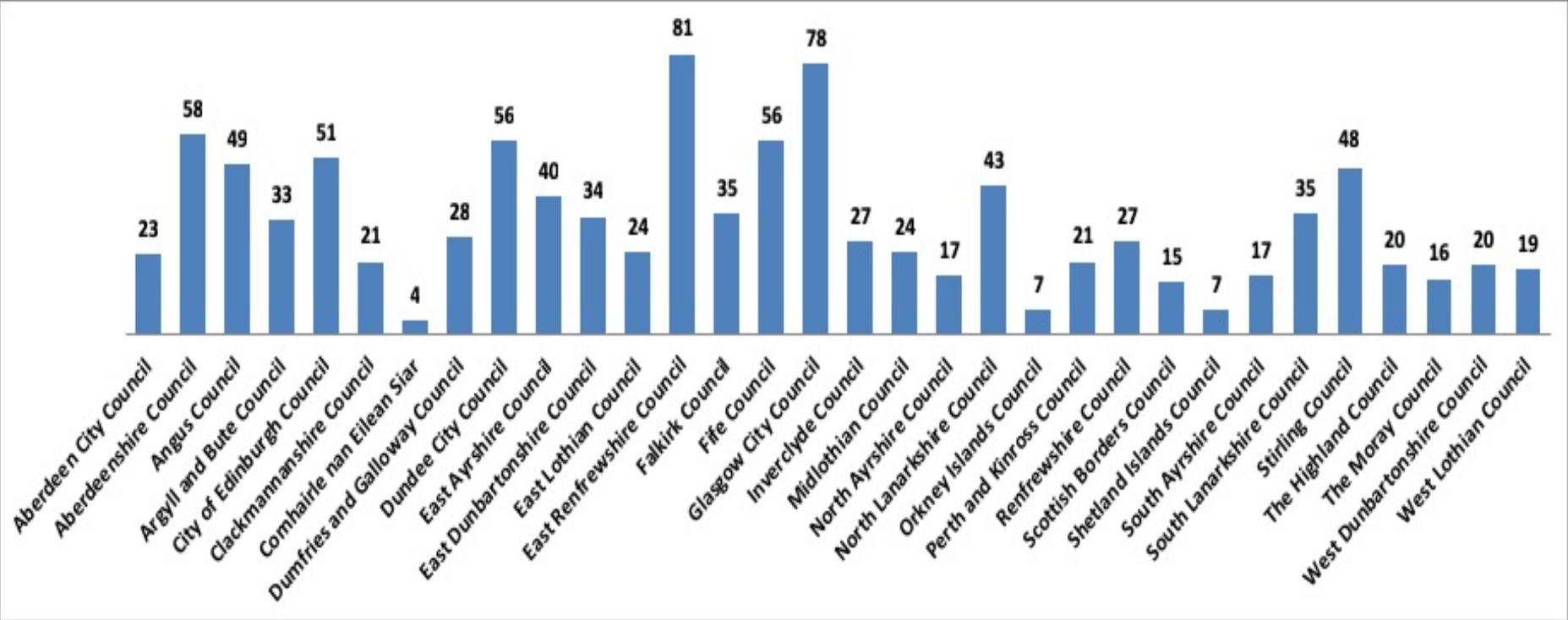
- 98% of the respondents to the survey were adult carers over the age of 18.
- 2% of the respondents were Young Carers under the age of 18.
- Since the legislation does not provide an official definition of the ages covered by the term Young Adult Carer, and to avoid any confusion, we did not use that as an option in our survey. However, as the following comment from one of the respondents highlights, it is likely that we will have received some responses from Young Adult Carers.



Young adult Carers are different from adult Carers therefore should have their own option instead of just young and adult. This is why they aren't given the support they need and it needs to be recognised in the new act

- We do need to consider how we can include the voices of Young Carers and Young Adult Carers in any future surveys or research that we undertake, to ensure that we are listening to their experiences of accessing carer support.
- We received responses from carers in all 32 local authority areas. Figure 1 shows the actual numbers of carers who responded from each of the local authorities.
- Only 1 of the 1035 carers did not respond to the question about which local authority they were a carer in.
- We had a relatively low response rate from the Islands and more remote areas, which we were expecting due to connectivity issues in those areas.

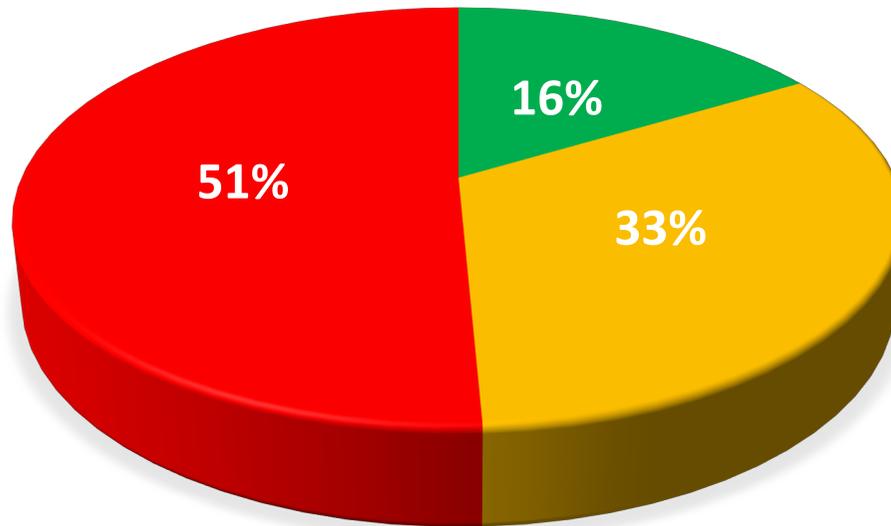
Figure 1 : Number of carers who responded from each local authority



(3) Are Carers Aware of the Carers (Scotland) Act?

- Only 16% of the carers who responded to the survey knew what the Carers (Scotland) Act was and the rights it offered to carers.
- Around one third (33%) had heard of the Carers (Scotland) Act, but were not really sure what the legislation was about.
- Around half of all carers (51%) who responded to our survey had never heard of the Carers (Scotland) Act.

FIGURE 2: PERCENTAGE OF CARERS WHO WERE AWARE OF THE CARERS (SCOTLAND) ACT.



- Yes, I knew about this
- Yes, I have heard about this, but not sure what it means
- No, I have never heard of this

- Carers who told us that that they were unaware of the legislation weren't just those who were new to the caring role; many had been caring for a considerable number of years, without any knowledge or access to support.

“ I had no idea this existed to be honest. I dont have any support and I care for my son who has autism and adhd. I'm also trying to hold down a full time job and care for my other 2 children. I never knew there was support for people like me. If I had I would be using it.

“ I don't know anything about rights. I just look after my mum and brother. Looked after my mum for more than 20 years.

“ Cared for my daughter for the last 10yrs and had no help or support and wasn't aware of the changes in law.

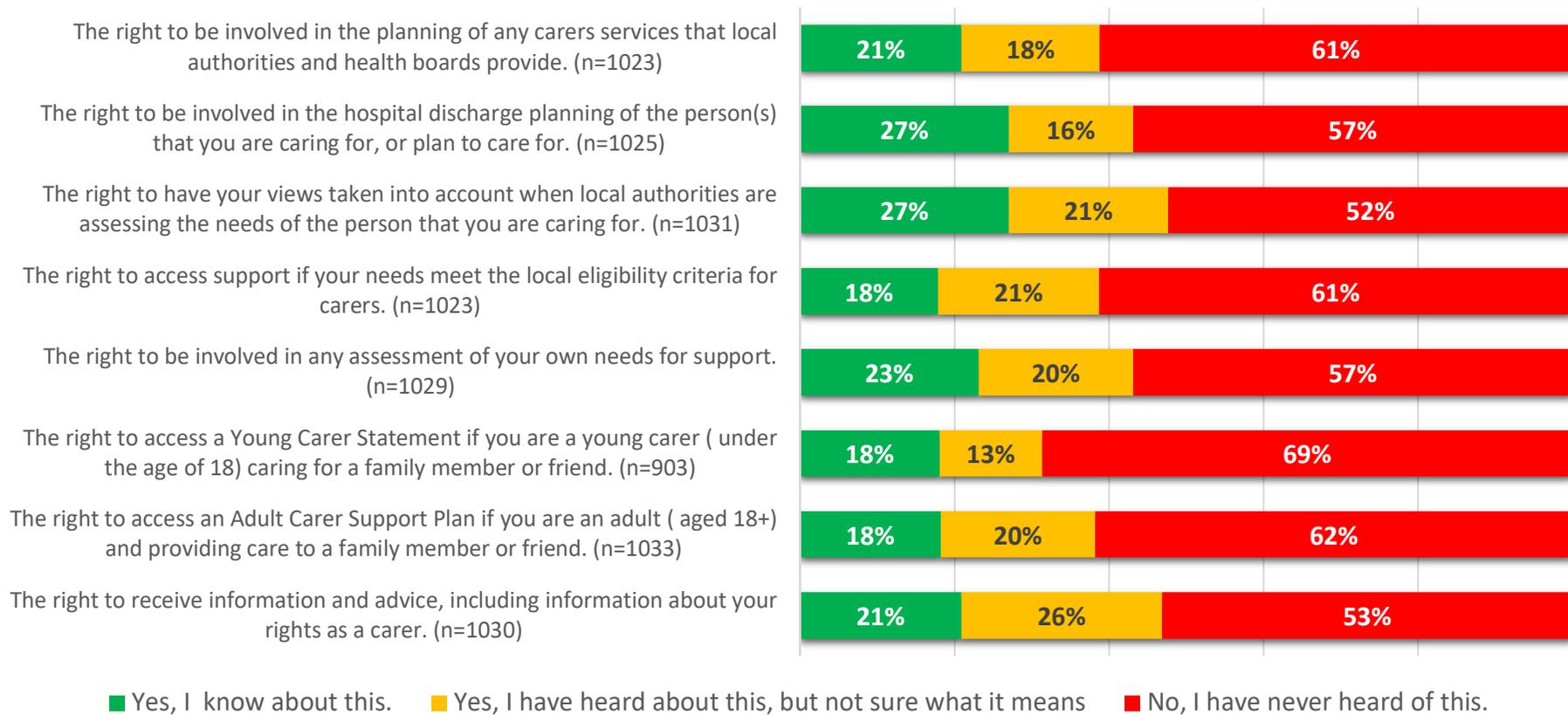
“ I have heard nothing about this act and have felt alone and abandoned when trying to get any help for my young daughter who has learning difficulties I worry about all aspects of her care and what future lies ahead for her

- We will be doing some further analysis of the carers' responses across each of the local authorities to see if there is any marked difference in awareness of the legislation across the different local authority areas.

(4) Are Carers Aware of their rights within the Carers Act?

The Carers Charter outlines a number of key rights that carers in Scotland have as a result of the Carers (Scotland) Act. This survey asked carers whether they were aware of some of these rights, and asked to respond using one of the following options : (a) Yes, they knew about this particular right; (b) They had heard about this right, but weren't sure what it meant; (c) They had never heard of this right.

FIGURE 3: PERCENTAGE OF CARERS WHO WERE OF THEIR RIGHTS UNDER THE CARERS (SCOTLAND) ACT.



The right to be involved in planning of carer services

- The Carers (Scotland) Act states that local authorities and health boards must involve carers in planning the carer services they provide, and must consider the views of carers and carer representatives when preparing and reviewing carer strategies and policies.
- 61% of the carers in the survey were unaware that they had the right to be involved in the planning of local carer services.



We are not asked about what carers want locally.

- Around one fifth of all carers (21%) in the survey knew that they had the right to be involved in the planning of carer services locally. However, many were sceptical about whether this was actually happening in practice and highlighted that real carer engagement was more than just having a carer representative on the Integration Joint Board.



The right to be involved in and have your views taken into account are just words.



As a carer representative on the IJB board I can say I was fully aware of the Carer's act but as for implementation I am totally unaware of progress. Appreciation of Carer's input is often discarded and in reality is the crux of future developments and understanding of needs and possible improvement of services.

- This appears to support previous findings from our survey with local carers centres¹ which highlighted that less than one third of local carers centres in Scotland agreed or strong agreed that carers and carer organisations had been involved in planning of carer services.

¹ Implementation of the Carers (Scotland) Act – The Experiences of Carers Centres in Scotland, (COCIS), December 2018

The right to be involved in the hospital discharge planning of the person that you are caring for

- The Carers (Scotland) Act states that each health board must ensure that carers are involved in the discharge of the person that they are caring for.
- Only a quarter of the carers (27%) in the survey knew and understood that they had the right to be involved in the discharge planning from hospital of the person that they are caring for.
- Over half of all carers in the survey (57%) were unaware that they had the right to be involved in the hospital discharge of the person that they were caring for.
- Carers can often feel unprepared and unsupported if they are not involved in discussions around the hospital discharge planning of the person that they are caring for, or intend to care for. Feedback from carers in our survey highlighted that many health boards are still failing in their duty to identify and involve carers in the discharge planning.



My husband has had significant chronic pain & mental health challenges resulting in an extended stay in hospital. I was not consulted fully when he was in hospital nor when he was discharged. He has been sent home and no one has contacted me to support my role as his Carer. I feel hugely let down given the hospital know the existing circumstances and my existing responsibilities with regards to my disabled son.



I only knew of some of my rights because I had to fight to get information and a care plan in place when my father was being discharged from hospital. 3 times prior he was discharged with nothing in place. It might help if Social Services and hospital/doctors gave you full information, that way you could all work together for a sensible caring outcome. Instead they are only interested in their own budgets or bed blocking in hospital.

The right to take carers' views into account when assessing the needs of the person being cared for

- The Carers (Scotland) Act states that local authorities must consider the views of carers when assessing the needs of the person being cared for, as far as that is 'reasonable and practical'.
- Only a quarter of the carers (27%) in the survey knew about their right to be involved in the assessment of the person that they were caring for, but did express some cynicism as to whether this happens in practice.



The council do not implement a service users needs if it does not fit in with their ideas.

- Over half of all carers in the survey (53%) were unaware that they had the right to be involved in the discussions around the assessment of the person that they are caring for. It would appear that carers are not always being made aware of this right when the person that they are caring for is being assessed for support needs.



I am experiencing real difficulty in getting an appropriate care plan put in place for my elderly mother. Social worker has not informed me that I have any rights at all...been trying to get this sorted for seven months now.

- Many carers, who do not currently have any social work involvement, also appear to be unaware of the processes involved to access support for the person that they are caring for. It likely therefore, that many carers are undertaking heavy caring roles without very little additional support.



We don't have a social worker so I don't really understand who would be accessing her needs. We have fallen thru the system....I feel very confused about what I can do.



We have a 12 year old daughter with profound physical and learning difficulties and we don't even have a social worker, so we know very little about how any of this stuff works.

The right to be involved in the assessment of their own need for support

- The Carers (Scotland) Act states that local authorities must involve carers in the assessment of their needs for support and decisions about how any such support is to be provided.
- Less than a quarter of the carers (23%) in the survey knew and understood that they had this right. However, many of these carers, who have tried to exercise their right to be involved in the assessment of their needs do not appear to have had a positive experience so far.



My local authority doesn't offer any support for me as an unpaid carer. I've only been assessed. I haven't even received a copy of my assessment.



We found out about it but don't understand details. Waited 7 months for a visit from social worker. Still waiting on assessment outcome. Indications are poor about level of support we will have.



Having asked for a Carers Assessment from the Council several weeks ago I've heard absolutely nothing from them about this assessment to which I am entitled. To be perfectly honest, I am of the opinion that the Council couldn't care less about carers

- Over half of all carers in the survey (57%) were unaware that they had the right to be involved in the assessment of their support needs.
- A number of carers were unaware of the support that they may be entitled to. Many are continuing in their caring role, without much support, because they either do not know who to ask for support or assume that they need to be providing “full time” care before they would be entitled to any support.



I just do what's needed for my parents (dad is disabled) I have no support, I wasn't aware anything was available. I have health issues too but probably like most carers, I just soldier on.



I have only just started caring for my mum this year and I thought because I work full time I wasn't able to get any support.

The right to access support if a carer meets the local eligibility criteria.

- The Carers (Scotland) Act states that the responsible local authority must provide support to any carer who has identified needs (which meet local eligibility criteria) that cannot be met through support provided to the person being cared for, or through general local services.
- Only 18% of the carers who responded to the survey understood their right to access support if they met the local eligibility criteria. A further 21% of carers had heard of this right, but were not too sure what it meant.
- Carers highlighted that it was not always easy to find out what the local eligibility criteria was in their local area. This supports our findings from research that we carried out in October 2018², which also highlighted that around 20% of the local authorities had still not published their local eligibility criteria online, which legislation states should have been published by 31st March 2018.



I know all about the carers act but as a single mum of 4, with 3 children on the autism spectrum (2 now adults) we get nothing in the way of support . What exactly is the council's eligibility criteria? It's a mystery!

- Almost two-thirds of the carers (61%) who responded to the survey were unaware of their right to access support if they met the local eligibility criteria.
- Limited availability of universal services and early intervention approaches in some local authority areas, alongside the local eligibility criteria for support being set at substantial or critical meant that many carers with low or moderate needs were unable to access any support until they reached a crisis point.

² Local Eligibility Criteria for Carers in Scotland, (COCIS), October 2018

“ In our local authority, only 1 carer has their own plan. Crisis is a prerequisite in this local authority to access a plan!

“ Local care criteria too critical for this act to be of any use to me

“ It's all very well having rights but if the eligibility criteria is set so high as to exclude provision, what's the point?!

- A number of carers were also critical of the decision to allow local authorities to set their own local eligibility criteria. The lack of carer involvement in developing the local eligibility criteria in some local authority areas has led carers to believe that the local eligibility criteria is there to prevent rather than support them from accessing support

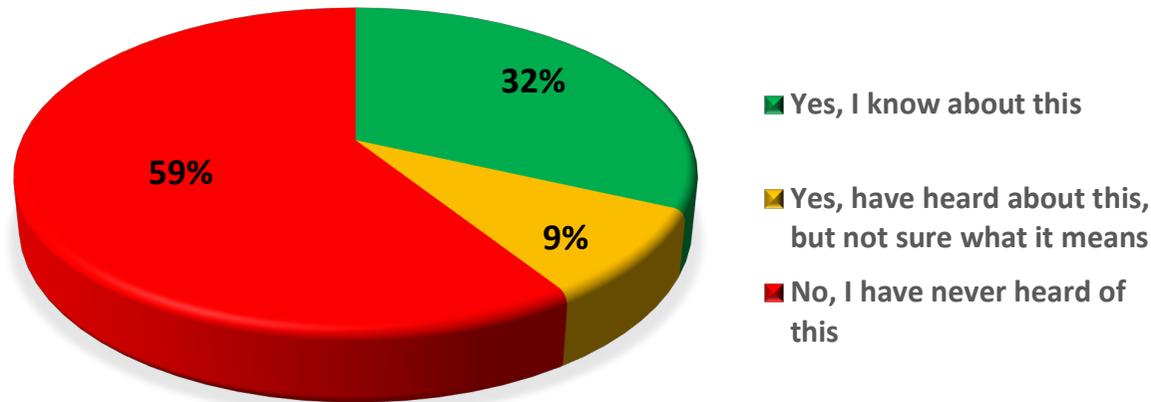
“ Our council are intending having the local eligibility criteria so high no one will benefit. It was a mistake for the government to leave the eligibility to local councils, especially ones who do not care about unpaid carers.

“ Surely the right to access support should not depend on whether your needs meet the LOCAL eligibility criteria for carers. This should be Scotland-wide criteria.

The right to access a Young Carers Statement if you are a young carer.

- The Carers (Scotland) Act states that the responsible authority must offer a young carer statement to anyone they identify as a young carer, or for anyone who meets the definition of young carer and requests one.
- Only 13% of the carers who responded to the survey knew and understood the right that young carers had access a young carers statement
- 69% of all carers who responded to the survey were not aware that young carers had the right to access a Young Carer Statement.
- Out of the 22 young carers (under the age of 18) who responded to our survey, 59% had never heard about their right to access a Young Carer Statement. Almost one third of the young carers who responded to the survey had knowledge of their right to access a Young Carer Statement.

FIGURE 4: PERCENTAGE OF YOUNG CARERS WHO WERE AWARE OF THEIR RIGHT TO ACCESS A YOUNG CARER STATEMENT



The feedback from young carers in our survey suggests that more work needs to be done by local authorities and organisations who support young carers, to ensure that they are able to access a Young Carers Statement if and when they request one.



Not enough information, support or services for Young Carers under 16/18



I had some support from my local young carers group however I don't know of any other support I could have received. Also, I am now a university student but don't really know where I stand as a 'carer' cause I am not home all the time. I am interested to look into the new carers act though.



I have asked my social worker about carer plan and young carer plan but the impression I got was that no one in the office knew what it was or how to implement it therefore was brushed aside.

The right to access an Adult Carer Support Plan if you are an adult carer.

- The Carers (Scotland) Act states that the responsible local authority must offer an adult carer support plan to anyone they identify as an adult care, or to anyone who meets the definition of an adult carer and requests one.
- Only 18% of the carers who responded to the survey knew and understood that adult carers had the right to request an adult carers support plan
- 62% of carers were unaware that adult carers had the right to access an adult carer support plan
- Once again, the comments from the carers highlighted that even if carers were aware of their right to access an adult carer support plan, this did not necessarily mean that they would get one; it very much depended on the willingness of their local authority to offer and undertake an adult carer support plan.



I am finding it very difficult to get a support plan for myself or the person who I care for (my husband). Getting support either in the form of a plan or otherwise is an extremely frustrating task especially when the money isn't available !!



The social workers were well aware of my distress and being at the end of my tether and gave me no advice about what I could access being a carer. I have been a carer for nearly 25 years to two disabled (now adult children with lifelong severe disabilities) All I want now is to make sure my children have supports in place so I can die in peace.



The social work department in this area, try and put you off assessments. I have been told I am not entitled to a carers assessment by social work and have little help accessing anything for my son.

Previous experience of trying to access support for the person that they are caring for has made many carers cynical of the level of support that may be available to carers now.

“ Hard enough to get support for children who need it due to disabilities. I will be amazed if unpaid carers get any support & we certainly won't be told of anything.

“ All great on paper but the support isn't there for the person let alone the carer.

“ I have never had any help for myself despite caring for 2 of my grown up children even though I have contacted social work and other agencies.

“ It won't make any difference. If I can't get any support for one disabled child, and can't spend the funding given for the other because there's no resources, what point is there in asking or having a carers plan! I can't even get my disabled children's needs met individually, never mind together so I could have a break.

The right to receive information and advice, including information about your rights as a carer.

- The Carers (Scotland) Act requires local authorities to have a local information and advice service for carers. These services must provide information and advice about a number of things relevant to carers, including the carers' rights as set out in the Carers' charter.
- 21% of carers in the survey were aware that they had this right to receive information and advice relating to their caring role.
- Just over half of all carers in the survey (53%) were unaware of their right to receive advice and information.
- Carers who are registered or in contact with their local carers centres appeared to be more informed about the new legislation and their rights to access to support.



Information received from my local carer centre has been fantastic and invaluable.



Local carers centre has been excellent at updating and asking our thoughts on upcoming act and their role in it



I received information on the Carers Act and how it relates to me from a local carers organisation. Without them I would not know anything about my rights as a carer.

- However, not all carers are able to access or are aware of their local carers centre. A number of carers were only aware of the new legislation and their right to access support because they had read about it online or had heard about it from other carers.

“ I've only heard about this from some facebook pages, not my local authority. Have no idea what it means to me as a carer

“ No one has ever given me information about my rights as a carer. Any information I have, I have read about it myself.

“ I only know about this, because I am a member of a parent carer group. Otherwise I would not be aware at all.

“ I am possibly only aware of the carers act and what it implies due to self interest rather than being informed by an official body!

- Social workers and health care professionals who are supporting a person with health and social care needs are often the first point of contact for many new carers. However, carers do not appear to have received much information, advice, or signposting to local carer services from local authorities and healthcare professionals.

“ I have not received any info from my local authority. They appear to be ignoring Carers rights and any request for information about Carers Act

“ No information or communications to Carers by our local authority. They're scared they will have to actually support unpaid Carers and spend money doing so. They are a disgrace and shirk all responsibilities to disabled persons and their Carers.

“ The only reason I know is because I made myself aware, no one has mentioned it to me in fact at my GP practice I was told I wouldn't really want to be labelled a carer for my husband

“ Social Work haven't even mentioned the new carers act to me, far less gone into what it actually means to us.

(5) Key Recommendations

The findings from the survey has highlighted that even though it's been almost a year since the introduction of the Carers (Scotland) Act, many carers have yet to see any real change in terms of accessing support for themselves and for the people that they are caring for. Less than half of all carers who responded to our survey were aware of the Carers (Scotland) Act and even fewer were aware of the rights that unpaid carers in Scotland are entitled to under the new legislation.

Based on the responses we received from carers, we propose the following recommendations to ensure that carers are better informed about their rights and are better able to access the support that they are entitled to.

Recommendation 1: Resources to implement the Carers (Scotland) Act

- Many of the carers highlighted that without adequate resources and long- term funding, the Carers Act legislation will end up becoming yet another missed opportunity for carers in Scotland.
- Resources are needed to ensure that carers who request an ACSP or YCS are not waiting for months on a long waiting list.
- Resources are also needed to invest in universal and early intervention services to ensure that carers do not need to reach a crisis point before they are offered any support.



Having rights will only work if there are enough resources and money put in to uphold those rights and there isn't. I've asked for an urgent re-assessment of my mum as her mobility has deteriorated dramatically and we're on "the waiting list" but it'll probably be "several months" before anyone comes out. In the meantime we struggle on, doing the best we can and getting support from the Carers Centre and other carers. Carer's Act is a great idea in theory but in practice it's just another bit of meaningless paper.

Recommendation2 : Better awareness for health, social care, and education staff

- Social workers, healthcare professionals and education staff are well placed to identify carers and young carers who may not currently be receiving any support. However, the responses from carers in this survey has highlighted that there is a lack of understanding about the legislation among many health, social care and education staff.
- Health professionals across Scotland appear to be unaware of a carer's right to be included in discussions around the hospital discharge planning of the person that they are caring for.
- Local authorities and social workers appear to be unaware of the specific duties within the Carers (Scotland) Act.
- Schools are missing opportunities to identify and signpost parent carers and young carers.
- More awareness and training is needed to inform frontline staff of what the Carers (Scotland) Act is and where to signpost carers for further support.



I am a qualified social worker, and now a full time carer having giving up work to take on a full time caring role. My recent experience of practitioners in my local authority is that they are ill informed regarding the rights of carers. 19 months after taking on a full time unpaid caring role I am still waiting for a carer's assessment.



My wife receives Disability Living Allowance after a sudden medical condition drastically reduced her mobility and ability to care for herself two years ago. She now relies on me for many things including cooking all her meals. I have never been informed by anyone of what I may be entitled to or where to go to find out. The Carers Act has never been mentioned to me by HSCP, DWP or NHS.

Recommendation 3: Recognising that carers and cared for people have diverse support needs

- People of all ages provide care to family members or friends who have a range of different health and social care needs. Services and support for carers need to better reflect the diverse background and caring circumstances of carers.
- Any assessment of a carer's need should take into account that every carer's circumstances are unique and that any support offered should reflect this. Assumptions should not be made about the willingness and ability of carers to provide care to family members.

“ Council don't care about gypsy travellers !!! They and don't make it easy for us to have those services ! like we are not deserving ! And we can look after our own !! but we also need the help that's out there ! But it's never offered anyway ! So how would we no ask for help .

“ As a carer of a young person with autism I feel there is no support whatsoever in terms of accessing autism support services, I think this is because my young person has high functioning autism and therefore it is assumed I have no needs as a carer. Which is obviously ludicrous, but seems to be an opinion shared widely by council and support services

“ Senior practitioners have made statements like, " Your needs are met within the care package for your brother" Completely failing to recognise that I have my own needs and outcomes which are separate from my brother's.

Recommendation 4: Improve access to information and advice for all carers

- Local carers centres have been commissioned to provide information and advice services to carers across many of the local authorities in Scotland. There was overwhelming support for the role that carers centres are playing in local communities and many carers highlighted that their local carers centre have been their only source of support, advice and information about their rights.
- However, carers often only contact their local carers centre when they are close to a crisis point. It is therefore imperative that other services and organisations that carers come into contact with e.g. health, education, and social care, also take on a greater role to raise awareness of the rights that carers are entitled to.
- Carers who have heavy caring or work commitments often find it difficult to access their local carers centres during office hours. It is important that there are alternative arrangements put in place to enable more carers to have the opportunity to access information and support.
- All information provided to carers should be available in easy to read and accessible formats



I would like to have more information on all of the changes but I need them broken down into simple to understand ways



I am working and caring for my own family as well as caring for mum who is disabled and has Alzheimer's. Most of my time is spent running around like a headless chicken. I can't even get time to call or go to the Carers Centre as by the time I'm finished work/meetings re mum the resource is closed.



There is a carers organisation but cater more for the elderly rather than those who like myself have/care for children with disabilities and mental health problems. I never knew anything about this act and mainly find out things through fellow carers or social media like this survey today. I am a single parent, have no support as a Carer or support from social work for my children.



The information is all aimed at Older adults. I work with over 20 young carers and NONE of us know about support - it an absolute disgrace!

For any enquiries regarding this report contact

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