

Listening and Learning from Unpaid Carers

April 2021



In coproduction with



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Healthwatch Bristol, North Somerset and South Gloucestershire is a charity (No: 1158487) and a company limited by guarantee (England and Wales No: 08187141). Registered office 3rd Floor, The Sion, Crown Glass Place, Nailsea BS48 1RB

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About Healthwatch North Somerset

Healthwatch North Somerset's (HWNS) statutory duty and remit is to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say about their care, including those who are not usually heard. We ensure that their views are taken to the people who make the decisions about services. Our expertise in engagement and coproduction means we can deliver consultancy work to local authorities and other commissioning partners.

We share feedback with Healthwatch England, NHS England and the Care Quality Commission (CQC) to ensure that the community's voice is heard at a national level. We make public all findings from work with patients, families, and Carers.

We give information and signpost people to find specialist help. We work closely with local community groups and organisations to support people to make informed choices about their care.

Our Vision is Simple

Health and care that works for you.

Our Purpose

To find out what matters to you and to help make sure your views shape the support you need.

Our Approach

People's views come first - especially those who find it hardest to be listened to. We champion what matters to you and work with system partners to find solutions. People are at the heart of everything we do.

Our staff and volunteers identify what matters most to people by:

- Visiting services to see how they work.
- Running surveys and focus groups.
- Going out in the community and working with other organisations.
- Networking with Patient Participation Groups who have their ear to the ground.

Our Ethos

"Healthwatch is committed to promoting equality, and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects for all."

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Introduction

North Somerset council (NSC) are working with local partners such as the Clinical Commissioning Group, Carers Support Alliance, Alzheimer's Society, and young Carers, to develop a New Carers Strategy. This co production work is to inform and develop a new Carers strategy for unpaid Carers in North Somerset 2021 - 2024

HWNS were asked to engage with unpaid Carers through focus groups and structured telephone interviews to give them the opportunity to tell us more about what support and services they would like to see in place over the next 4 years to inform the new Carers strategy. This qualitative report that has collated their views into themes based on the lived experience of unpaid Carers over a short period in early 2021.

Background

There has been much research over the years to gain understanding and learn from Carers. It has been widely acknowledged that many Carers do not see themselves as Carers because of the relationship they have with the person they care for, they see themselves as a partner, parent, child, or friend first. [1]

In 2015 The North Somerset Multi agency Carers strategy 2015-2018 [2] set out how adult Carers will be supported in North Somerset and was based on the four priorities of the Coalition Governments 2010 review of the National Carers strategy [3]. North Somerset Council said "Carers will be universally recognised and valued as being fundamental to strong families and stable communities" [4]

In 2019 NHS England launched its 10-year Long Term Plan that includes its commitment to better support and identify Carers with Carers passports which aids the provision of support, services, or other benefits. [5]

Executive Director Helen Walker, of Carers UK said *"We welcome the Plan's ambition to.. speed up the identification of unpaid Carers and support them to address their own health needs through summary care records and Carer passports. Measures to support Carers' access to back-up support in an emergency will also be appreciated by Carers who are too often left to manage a health crisis alone. The real test will now come in the implementation of the Long-Term Plan in local areas across England."*

In 2021 a new Carers strategy is being developed by North Somerset Council in collaboration with local partners, Carers Support Alliance, Alzheimer's Society, and the Clinical Commissioning Group for 2021 - 2024.

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Aims and Objectives

The aim of this project was to hear from unpaid Carers 18 years plus in North Somerset about what support and services they would like to see in place over the next 4 years.

- To hear from parent Carers and adult Carers 18 years plus
- To put the outcomes, feedback and suggestions for change and improvements together in a report to inform North Somerset Council for developing the Carers Strategy.

Executive Summary

COVID 19 exacerbated the experience for unpaid Carers. Their feedback points to areas where health and outcomes for Carers would be improved across the themes; Communication, Support, Assessments, Sign posting, Respite.

All unpaid carers recommend that the strategy incorporates the following good practice;

- Provide support to register at a GP surgery to give benefits such as electronic flagging on notes for the cared-for and on the carers notes.
- Ensure that each assessment is 'Needs-led' so that each person's unique requirements are supported and provided for.
- Carers are given advocates to speak up for them and help navigate the system.
- Carers are given ongoing support in the form of a co-ordinator for their Health and Social care needs.
- There are more practical support facilities such as disabled spaces and public toilets with changing facilities that cater for children and adults.
- The strategy emphasises ways to support self-care, as Carers can forget to look after themselves

Parent carers recommend that the strategy also incorporates the following good practice;

- Both parents should be registered as a Parent Carer.
- The council provides specialist staff training and increase their staff numbers to focus on inclusion and support at existing community clubs

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- A care pathway or plan is put in place to support families and schools when children are moving from a primary school to secondary school.
- A transition pathway is put in place to support and signpost families and their child in the transition from child to adult care.

Adult carers recommend that the strategy incorporates the following good practice;

- Focus groups are run for Carers quarterly by someone who has been a Carer or understands what it is like to be a Carer.
- The council website has a regularly updated list of respite places and to include what type of respite is on offer.
- Signposting is improved for the emergency card which should combine with a Passport to give carers easy access to local services, benefits and support.

Methods

HWNS had initial consultation between NSC, their commissioned support service for Carers, Alliance Carers Support in February, and March. Our work was to expand engagement to support the Carers Survey questionnaire that completed on the 21st of February 2021. We discussed expanding on the questions asked about services and support for Carers.

During these meetings we planned our questions in relation to the following

- Carers health
- Caring role
- Managing at home
- Time for yourself
- Services and support that Carers currently have that are working
- Services and support that are not working
- Suggestions to help improve support and local services
- Carers experience during lockdown

Questions to ask during focus groups and interviews

- Where would you go to find support?
- What are the things that would make your life easier as a Carer?
- What support do you receive from local services to help you?
- What support would you like from local services?
- How has your experience during lockdown been?

Qualitative feedback was gathered during zooms focus group sessions and telephone interviews/discussions. Facilitation and note taking was provided during

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two of the focus groups by Parent Carers Working Together (PCWT) support group. Although the intention was to ask the questions in a structured way, it was more fitting to listen to what Carers had to say and ask the questions as the conversations dictated. This meant not all questions were asked directly.

HWNS approached local organisations and individuals known to us and used social media inviting organisations to share. North Somerset Times Online promoted our engagement work offering the opportunity to join focus groups or have a telephone interview by contacting HWNS. A direct email and phone number was provided.

In co-production with PCWT two focus groups were set up. PCWT helped to promote the focus groups on social media and within their network. A third focus group was organised in co-production with Alzheimer's Society Bristol North Somerset and South Gloucester.

To reach as many unpaid Carers as possible in a short time frame, HWNS emailed and telephoned organisations and Carers known to us and NSC. We signed a shared data agreement with NSC for this project and reached out to 30 of these contacts.

Due to the time constraints, capacity, and lockdown our reach and engagement was not as wide as we would ideally achieve. Covid restricted the ability to meet in person and join groups however we were flexible with dates and times where possible when offering telephone interviews and organising focus groups.

Focus Groups

Parent Carers focus groups were organised in collaboration with parent Carers Working Together we had two focus groups. First focus group was with 6 Carers and the second focus group with 9 Carers. A total of 15 Parent Carers.

A third focus group was organised in collaboration with a Dementia support worker for North Somerset at Alzheimer's Society Bristol, North Somerset, South Gloucestershire. People caring for their loved ones with Dementia attended this focus group.

A fourth focus group was organised by Healthwatch, the focus group was for Carers who cared for their partners with a mental health and/or physical disability.

Total Number of Carers attending Focus groups was 23.

Telephone call interviews

Parent Carers Individual telephone interviews: 4 lasting between 30mins - 1.5hours each. Caring for children with physical and/or mental health disability.

Adult Carers individual telephone interviews: 4 lasting 40 mins to 1.5 hours each. Caring for a family member with physical and/or Mental health disability.

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The total number of Carers interviewed by telephone was 8, total number of unpaid Carers listened to was 31.

	Parent Carers	Other Carers	Total Carers
Telephone	4	4	8
Focus Groups	15	8	23
Male	1	4	5
Female	18	8	26

Summary of our findings

This project was carried out during COVID 19 lockdown and as a result we heard the experiences unpaid Carers had experienced during those restrictions.

“Very little to no respite available”

“Family support improved due to forming bubbles because family members were furloughed”.

“Family support was worse due to isolation or shielding”.

“Information from the government about shielding and forming bubbles was not clear from the start”.

“Online Craft sessions have been great”.

“Neighbourhood support during the first lockdown was great, now we have settled into a routine there is less communication and offers of support as most things are in place for example: online shopping”.

“I really miss coffee mornings”.

The main themes emerging from Focus groups and interviews

There were several themes arising from the questions asked and during discussions in the focus groups and interviews. Responses were different for Parent Carers and Carers and they are included below. The common themed areas were:

- Communication
- Support
- Assessments
- Sign posting
- Respite
- What Carers say are working well

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Communication

Carers felt they could be valued more, listened to more and their experience and knowledge taken into consideration more. They want to be recognised for the knowledge they have and for people to listen to them when making changes. Some Carers felt the term Carer is confused as it also relates to professionals and they want to be recognised separately, as they are not paid.

The experience for all Carers

“I do not feel listened to and my knowledge of care and illness for my partner is not taken into consideration”.

“We need to be listened to and taken seriously. We want to be recognised for the knowledge we have and for people to work with us and listen to us when making changes.”

“I want to be recognised as a family Carer”.

The experience for Parent Carers

“We are professionals in our own right, we live with our family member 24/7, we know the ins and outs of what works and what doesn’t work and how situations and environments affect their behaviour.”

“If professionals recognised his needs more then maybe he wouldn’t have as many struggles as he has now, because we would’ve been able to identify things and put in place sooner.”

“We are the experts and know the most about our children. Professionals and schools need to listen to us.”

“We don’t want to see another Carers’ strategy but then nothing changes! We are fighting, overwhelmed, exhausted, battle weary, & not being listened to.”

Many Parent Carers said having to explain their story to professionals could be traumatic. A parent carer suggested:

“a one-page profile should be created and given to professionals at every appointment. This would be a front page on notes so professionals would have their child’s details and a brief history available prior to the appointments. This would help avoid the repetitive explaining of their circumstances. It would also allow more time to discuss the current issues.”

Parent Carers response to this idea:

“thank would be fab” “great idea” “amazing I love that idea.”

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“Lack of continuity, a lot of locum cover, seeing someone different every couple of months; Having to repeat yourself over and over again, there is lots of time wasted.”

Support

There was an overall feeling of exhaustion with little or no down-time amongst many Carers. The support in a crisis was noted to be overall great, however the ongoing support is what would make all the difference for many Carers. There does not appear however, to be support for help with issues as they arise. Many Carers said it would be great for someone to check in with them over a phone call or a coffee.

The experience for all Carers

“Not good at asking for help for myself it would be good to have someone who checks in on us every now and then.”

“Feeling exhausted as a Carer, its 24/7 with very little or no down time, it would be great to have someone check in on you occasionally.”

The experience for Parent Carers

“Child and Adolescent Mental Health Services (CAMHS) waiting list is long however it’s great once you get an appointment.”

“You are so exhausted as a parent it’s really hard to make changes on your own when trying to change behaviour patterns like sleeping and toilet training. If we had practical help then we would know if it was possible to make the changes really happen.”

Parent Carers say there needs to be more joined up thinking when it comes to health and social care. Some Parent Carers said when they were given a diagnosis for their child there was no follow-on support. They would like support and referrals to be easily accessed and suggested. They wanted help with co-ordinating all the various processes with specialists, referrals to therapists and where they were in the assessment process or what happens next. They said this would improve their own health.

“It feels like as a parent someone else should have an overview of your child’s journey to ensure things don’t get missed when paediatricians are ever changing.”

“Someone for me to go to who would know what is happening with referrals to health services and social services.”

Parent Carers say there is a lack of information and support available when transitioning from primary school to secondary school and that support varied depending on the school attended. Parent Carers would like there to be training for schools and health care staff on hidden disabilities and support for parents and

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schools during transition from primary school to secondary school. They suggested Young Carers groups need to be more involved in schools and for siblings to be supported at school.

“More support for school staff and parents during transition periods from primary to secondary and secondary to further education.”

“Transition from primary school to secondary school could be smoother if we were listened to as parents.”

“There is a lack of understanding around hidden disabilities.”

Assessments

All Carers said assessment forms/disability forms are ‘long winded’ and they recognise that although assessments are necessary they requested more awareness of and facilitation of support available when filling in the forms. There are organisations that can help with this, but many parent and adult carers were unaware of them.

“It would be very helpful to have an advocacy for Carers when it comes to form filling and support for when things don’t appear to be right as this would alleviate some of the stresses.”

“Care assessments are difficult over the phone as I am not good with paperwork.”

“it’s difficult to find quiet time to complete assessments.”

All Carers expressed the need for a holistic approach that takes their mental health, physical health and whole family situation into consideration including their financial support.

“Our physical and mental health needs should be considered together.”

“What happens if something happens to me.”

Parent Carers want assessments to be “needs-led” for their child and their family so that the care and support can be more tailored to individual needs. With the current assessments some Carers felt there was no support for them if they did not meet certain criteria and this meant they felt excluded and had to fight to find support.

“Disability assessments should have a needs-led approach rather than not meeting the criteria that makes you feel pushed out of the system.”

“People fall through the gaps with the current assessments, I am exhausted from fighting.”

Sign Posting

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All Carers pointed out that many services are not joined up and duplicated information. When people are first diagnosed there was either too much information or Carers did not know who to go to for further information and support.

“Navigating through the information there is too much given at once would be good to have it slowly.”

Parent Carers say it was not easy to find out about appropriate services and support. They asked for clearer signposting:

“Chasing to find your way around the system. No clear signposting for parents. NSC website needs to signpost more clearly, it’s not an easy website to navigate.”

“Joining the forum PCWT I am now discovering all these amazing resources that I never knew were there and haven’t been signposted very well.”

“Personally, I do not find the information on the council website easy to view and to navigate! It would be really valuable to make the information much easier to find rather than buried in various pages.”

Respite

All Carers expressed concern over their financial situation, and many were using savings to top up funding for extra care and respite services. They realise funding is not unlimited, however they felt North Somerset has had many service reductions over the past years and travelling to Bristol or South Gloucestershire had become essential for some groups and support. They would like a return of more local services.

Carers access to respite has been limited during Covid and very difficult to access for those with Dementia. Day care services are not operating normally due to Covid and Carers are greatly missing the time to talk with others in their positions and have helpful conversations.

“Access to respite has been very limited and many are missing this service, having to isolate is too distressing for people with dementia.”

“Greatly missing the time to talk and have conversations.”

“Once restrictions lift there is more need for coffee mornings, groups, tea dances and sing along sessions.”

Parent Carers views on respite were varied depending on the age of their child and family circumstances and that it would be helpful for some but not others. They said there appears to be good provision for high needs but less provision for moderate needs. Some parents pointed to a need for help with older children as there are less groups and activities for these.

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Parent Carers had the following to say:

"It would be good to have an extra pair of hands to help when you are out."

"Less groups and activities available as children get older."

"Transition from Child to Adult there does not appear to be much help once they leave school. There is a need for more support and signposting when children transition from child to adult services."

"There needs to be better holiday clubs."

"I would like just an hour or two a week so I can spend time quality time with my other child."

For all Carers better integration of the agencies involved would help the continuity of care. This was a big frustration, as Carers must explain the ins and out of individual needs to different paid Carers every time. It was recognised it would not be possible to have the same Carer every time however more continuity would be very helpful especially for those with high needs and for people with Dementia.

"We have different Carers every time, it's exhausting having to explain about my husband's illness and what his needs are."

"Times of visits are not thought out especially for those with dementia - too late in the evening or too early in the morning."

"We don't have the same Carers each time, after explaining where everything is and the specific needs for our child it leaves less time for us being out."

Time for yourself

When asked what time for themselves would look like Carers responses varied due to differing circumstances. Some had great family support, others were missing that support due to COVID 19 lockdowns and the changing circumstances. For Parent Carers there was also the worry of aging grandparents not being able to provide the support they used to. These are their self-care aspirations;

"Sit in the garden." "Go for a walk."

"30 mins peace in the evening -these can go on so long."

"Massage or spa treatment." "A nice meal out every quarter."

"Need support not just a babysitter - need someone who knows my child."

"Trying to get someone else to look after your child is really challenging - family can no longer do that role."

"You are on call 24/7 there are no breaks. You don't get those opportunities that would make a huge difference to relationships within the family."

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Carers were asked what would make life easier or what would good support look like, and they had the following to say:

“Using clubs that are already in place and most importantly providing good training for staff so that existing clubs can focus on being inclusive.” - Parent carers

“Communications to be regular and consistent in all areas of education, health and social care.” - All carers

“More disabled parking made available.” All carers

“More local clubs for singing, dancing, art and music for time out together but also it would help with detecting the early signs of dementia” - Adult carers

“On the council website a regularly updated list of respite places to include what type of respite is on offer” - Adult carers.

Good Practice and support

“Mobilise are very good.”

“‘Living with dementia’ courses very good.”

“Craft sessions during Lockdown have been great, equipment is delivered to your door then you follow an online session”.

“PCWT have been brilliant.”

“Dial at Weston disability services are brilliant..”

“Memory clinic assessment is good.”

“Department of work and pensions have a visiting team to help with filling out forms they are very good.”

“Alzheimer’s society are very helpful with giving information as its needed”.

“End of life care is good”

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- There are more practical support facilities such as disabled spaces and public toilets with changing facilities that cater for children and adults.
- The strategy emphasises ways to support self-care, as Carers can forget to look after themselves.

Parent carers recommend that the strategy also incorporates the following good practice;

- Both parents should be registered as a Parent Carer.
- The council provides specialist staff training and increase their staff numbers to focus on inclusion and support at existing community clubs.
- A care pathway or plan to be put in place that is tailored to the individual child and supports families and schools when children are moving from primary school to secondary school.
- A transition pathway is put in place to support and signpost families and their child in the transition from child to adult care.

Adult carers recommend that the strategy also incorporates the following good practice;

- Focus groups are run for Carers quarterly by someone who has been a Carer or understands what it is like to be a Carer.
- The council website has a regularly updated list of respite places and to include what type of respite is on offer.
- Signposting is improved for the emergency card which should combine with a Passport to give carers easy access to local services, benefits and support.

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We extend our thanks to all the Carers that took part in this project and the involvement of coproduction partners North Somerset Alzheimer's Society & Parent Carers Working Together.

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