



**healthwatch**  
Surrey C.I.C

# Designing support services for carers of people using mental health support

Giving Carers a Voice – July 2022

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## Introduction

As part of the newly awarded Giving Carers a Voice contract, Healthwatch Surrey (HWSy) was commissioned by Surrey County Council (SCC) to undertake engagement with carers of people using mental health support services and relevant stakeholders.

The aim was to inform the service specification for a new carers support service. Below is the brief for the process.

**Brief:** Surrey County Council in partnership with the NHS are piloting Service(s) for Carers of people using Mental Health Support.

This is a new service, arising from feedback received during the development of the Carers Strategy.

The specification will be co-produced with stakeholders, and it is anticipated that it will initially be piloted over two/three years to inform a longer-term approach.

The project had three phases:

**First phase:** Initial engagement forums were undertaken and a survey shared with carers.

**Second phase:** focus groups with carers, talking about the themes arising from the first phase, adding insight and developing ideas for the design of the specification.

**Third phase:** a workshop with stakeholders and carers to confirm key points for the specification

This report summarises the findings for each phase.

## First phase feedback

During this phase a number of carers gave feedback on the challenges they face through a focus group and survey. The aim was to inform the design phase of the service specification for support services for carers of people with mental ill health.

The feedback is set out in more detail in Appendix 1 but the key themes from the feedback were:

- Carers breaks
- Support for carers working with professionals and need help getting responses or need support to navigate service pathways
- Training for staff in working in partnership with carers
- Access to and continuity of practical support for carers and their wellbeing that is proactive and provides navigation of conditions and services via paid staff and peer support
- Information on conditions and raising awareness for those who may not see themselves as carers
- Space for carers to share their experiences with others

The themes were used as the basis for discussions in a series of follow up workshops, to further explore these and any other experiences carers wanted to feed back. People who had provided the feedback via previous groups and the survey were invited to attend.

## Second Phase Carers Workshops

We undertook three workshops with carers that had given feedback, to explore design ideas for the carers support service specification.

The workshops took place online on 30<sup>th</sup> and 31<sup>st</sup> May and 1<sup>st</sup> June, at different times of day.

A number of attendees cared for people, under 18 years and had specific feedback, so the summary below includes sections to highlight their feedback and design ideas.

It is also ordered in the priority the topics were given by the carers that attended the workshops.

### 1. Information on services and conditions and raising awareness for those who may not see themselves as carers

#### Insights

Almost everyone had experienced difficulties getting information about:

- mental health conditions and what to expect
- Support services for carers and where to find them
- Carers entitlements such as support services and benefits

Many referred to having to do their own research or join groups and peer networks to find out what was available.

For example, there is a lack of information on the Surrey and Borders Partnership NHS Foundation Trust website under carer. It would be useful to have a map of the services and support in the area. This would especially be helpful for when you're new to being a carer.

*"how are we supposed to know about these without doing our own research?"*

Carers Information Packs were mentioned but no one had seen them recently, certainly not during or since the pandemic.

The Dementia diagnosis process was different to the experiences of those who went through the mental health process. Dementia was more structured,

*"I felt overwhelmed by the information available to me, it wasn't clear to me what options I had available."*



## Under 18s

No one we spoke to had received any information from children's services or schools on support available for carers/parents.

Attendees all agreed that there is a massive gap with education and early intervention.

It was felt there was a lot of 'parent blaming' by professionals but little information to back it up.

Everyone described having to do their own research or utilise peer networks to get any information. However it was hard to find the right networks.

One of the attendee's children were assessed for Autistic Spectrum Disorder and was given a 30 page document which went through what was wrong. This document included a page with further support but there was no structure to what they were given, she felt it was a case of

"there you go, the rest is up to you."

All she found out was via Facebook groups, and recommendations.

"I've had to learn about this, this is what takes up my time, and no one has ever checked up on me, it's been incredibly tough."

## Design ideas

It would be helpful that when you appear to a service, someone takes responsibility for giving you information to know what's available to you, offer a follow up to see how things are going, and talk about what are the next steps.

Carers Information Packs should be revisited and more easily available.

The same information should be available via a single point of access and in the range of formats and online/offline.

A single phone line is needed.

**Under 18s** - One stop shop to be brought into schools, a support system in schools would be a huge step.

"In an ideal world, as soon as your child is diagnosed, you're assigned a case worker to support you and provide information. That would be hugely beneficial."

The term 'carer' should probably not be used with under 18s as those caring for children would most likely describe themselves as parents or guardians.

2. Access to and continuity of practical support for carers and their wellbeing. Proactive paid staff and peer support to help carers navigate the system and the support available to them

### Insights

Carers spoke about the challenges of having workers assigned to them who then change or disappear altogether. There did not seem to be a shared database of every carer who may need support. They were often unsure who to get in contact with to raise this.

“Due to many things, like changing of staff, information and communication just seems to go missing. Systems keep changing, that’s the main problem!”

We heard a positive story around social prescribing –

“My GP put me in touch with the social prescribing team, I have been speaking to a lady who is fab. She seems to know and have answers for everything I throw at her.”

The frailty hub also received some positive feedback –

“The frailty hub was great. I felt like I was on my own, I had too little support and now I know where this support is. It has been a godsend. There should be hubs for everyone. Knowing they are there has taken a weight off of my mind and less stressed.”

“Action for Carers are very helpful, but it’s a long process to get to someone who can help.”

Carers did not want to have to keep repeating their story.

### Under 18s

There was conversation around the lack of support from schools. One lady’s son tried to kill himself and has not been back to school since.

“These problems could be avoided if his symptoms were captured and us carers were supported earlier on.”

“The school didn’t listen, if I had been heard when my son was 5, we wouldn’t be where we are now.” They would call when he was lashing out but they wouldn’t see what the issue was behind the scenes causing him to lash out.”

You shouldn’t have to wait for a diagnosis to get support.

Family Voice Surrey was mentioned as a form of support to one attendee, who were outraged when they heard how they had been treated her and her son. The CEO ended up helping her write an email to correct the issue.

### Design ideas

All agreed it would be beneficial to have one case worker assigned to a carer at the beginning of the process, to touch base monthly and to provide different information at the different stages.

*“Having someone to check in on us would be fantastic. By giving us the information, we will know where to turn.”*

For under 18s in addition there needs to be a support mechanism in primary and secondary school, either a worker or a peer support group

## 3. Carers Assessments

### Insights

Less than half of the carers we spoke to in the workshops had had a carers assessment, almost none of those who cared for someone under 18yrs had been offered one.

Those that had had carers assessments had not found them very effective, describing them as too many tick boxes and not giving the opportunity to talk about things truly impacting the carer.

The financial assessment was also a sensitive area, but more about how carers were left feeling rather than any objection to having to pay for services.

*“They were condescending, almost as if we should be grateful we’ve got anything, this wound us up.”*

People were often not told at the point of assessment they could ask for a review if circumstances changed, and often did not get the information they needed at the assessment.

Carers described difficulty with putting a figure on the number of hours they were caring, as it fluctuated from day to day and week to week depending on how well the person they cared for was.

Carers did not want to have to keep repeating their story.

### Under 18s

Almost no one we spoke to had been offered or had had a carers assessment. Tick boxing was mentioned a lot throughout the session

*“There’s a lot of tick boxing and not an awful lot of doing.”*



An attendee did ask CAMHS for a carers assessment yet this was refused and was told 'it wasn't part of our job'.

"It's like they live in a box, they don't know what the other people do and there is no coordination and networking so that is left to me, the carer."

One carer who did have a carers assessment did not have a good experience and never heard back after the carers assessment. They didn't know carers assessments were a thing until she stumbled on it.

"We need to know the different options that could help us and they are only finding out things by stumbling across it. Having more information would decrease the amount of times we have to call them!"

### **Design ideas**

The carers assessment needs to have less tick boxes and be more of a discussion and wide ranging assessment of the carers situation. This will open up opportunities where carers can be supported more widely with relevant information and signposting.

This could also help people to feel they are still being directed to free support, even if they have to pay for some services.

Better sharing of the carers assessment needs to be explored to reduce the need for carers to retell their story.

The benefits of having an assessment should be explained to the carer by properly trained staff who understand what these are. They then should have the knowledge to tell the carer what is then available in the way of support

## **4. Stress and wellbeing**

### **Insights**

Carers talked about the constant level of stress and anxiety which inevitably impacted on their own physical and mental health.

They also talked about grief for the person that the person they care for could never be. This was particularly acute for parents of under 18s.

### **Under 18s**

Parent carers also talked about the additional pressures if their child did not attend school.

One attendee's son had lost his confidence due to not attending School.

"He was supposed to have his EHCP looked at legally over a year ago, and with that year he's been sat at home, hardly going out and he's now lost his social skills, confidence and now his mental health has been impacted. He

should have had support from services coming into the home which has not happened. This would have helped the carer massively.”

The connection between genetics and diagnosis was discussed. Lots of parents may also have a diagnosis so information provided in a way they understand is important. Do they need an advocate? Are they struggling themselves? Is the parent capable of doing this role? Do they have help? This is what the carers assessment should do.

### Design ideas

Carers agreed that a significant way to reduce their stress would be effective support from services for the person they cared for. Attendees were assured their feedback about what professionals could do differently was being shared.

Mental health support may be needed for carers. Carers support services also need to ensure they include this need in their offer.

## 5. Working with professionals and communication

### Insights

Carers described significant challenges with the way mental capacity and privacy were managed by professionals, often leading to them feeling excluded from discussions about the care of the person they care for. There was a conversation around the triangle of care and where has this gone? It was felt there has been significant disruption over the pandemic and this needs to be re-established with professionals.

Carers felt they could give important intelligence to inform professionals but they were excluded, particularly if the person they cared for lacked insight and so would give a different perspective to the one the carers saw.

Attendees also commented on how communication can be one way, when services want the carers help to work with the person they care for, they communicate but also expect things to happen quickly. When the carers wants the same thing from the professional, it often doesn't happen.

There was conversation around the community mental health teams and the lack of staffing. One lady had a positive experience where she as the carer was the priority, and they would meet every 6 weeks, but the support would be there as and when she needed it.

“I didn't have to explain things, she already knew, and you could be honest and she not only came back with emotional support, but practical support too, I managed to have some counselling. There was a trust, that was the nicest thing, we could speak to her and she would keep us updated. Now she's gone, there's a real gap.”

## **Under 18s**

There was a lack of staffing with CAMHS too – one lady’s daughter had no idea who her case worker was or what they’re supposed to do. She’s currently on her third case worker because they keep leaving.

“I’ve had times when she’s suicidal, I’ll email because it’s quicker to get a response, and I copy the lead in on everything because it’s the only way I get a response. I get asked is she likely to commit suicide, am I qualified to answer this?”

One lady’s son got seen only because she kept pushing with the CEO at SABP and her son tried to take his own life. She also has not received a carers assessment. Even though her son is under social care due to the suicide attempt at a young age, he’s classed as a child in need, yet they haven’t offered the family any help.

“The effect of what is there and how people communicate is important too, when your child is diagnosed, there’s a period of grief you go through, you’ve lost the child and the future they thought they’d have. I don’t think this is recognised at all. No support around the mental and emotional impact.”

“It’s hard to get some support and understanding when your daughter doesn’t present in a public setting. I can tell them what’s happening at home, but unless I get evidence of this they just offer mindfulness and meditation.”

Attendees wanted professionals who understood the relevant pathway to share information on the pathway with them, understanding what to expect next was very important.

Attendees also commented on how communication from professionals reduces significantly once the person they care for is 18yrs.

## **Crisis**

Safe Haven was praised for their response in a crisis but are not open 24/7.

Carers felt they were often not listened to when the person they cared for was approaching or in the midst of a crisis.

## **Mental health inpatient services**

This was a significant area for communication with a significant lack of access to staff to discuss what was happening with the person they were caring for. Some carers talked about their input being actively ignored. Carers were directed to the Patient Advice and Liaison Service (PALS) but there was a delay in their responding.

## Design ideas

Having someone outside of the professionals but aligned with them would be helpful.

Re-establish the Triangle of Care model across all services.

## 6. Space for carers to share their experiences with each other

### Insights

The majority of workshop attendees were aware of and/or attended peer support groups, both online and face to face before the pandemic and recently.

Most had struggled to find out about them and what they offered.

There were challenges with having face to face groups locally enough and at the right times of day.

Everyone agreed that groups needed to be for specific conditions where the experiences of carers were more likely to be in common with others in the group. Support groups should not be generic.

However groups were not for everyone, some carers felt worse after hearing other peoples negative experiences.

### Under 18s

There tended to be more use of WhatsApp and Facebook groups that provided a lot of support and signposting from peers. There is no information on which are the most suitable forums to use.

There was praise for Family Voice.

“People that know what you’re going through are the best people to be around. Parents need a single point of access.”

### Design ideas

Specialist speakers about conditions would be useful to understand what carers might need to expect and prepare for.

Speakers from support services, social prescribers and care navigators would also be helpful.

Forums need to be a blend of online and face to face, with face to face being particularly important for emotional support.

“Before they set up support groups, please could they check what already exists. I'd rather they put the energy into things that don't exist and are needed. If there are groups that exist then signposting to them might be what's needed.”

## 7. Carers breaks

### Insights

Carers have seen a reduction in the amount of break available and are aware there is high demand for services like Crossroads.

“I feel lucky because Crossroads have a waiting list which lots of people are waiting for.”

It was felt that current offers of half a day a week do not give the amount of time needed for a real break. People described only being able to nip out to do some errands.

A carer expressed gratitude to a programme called Hope, which was respite care for young people. It is a place for them to go instead of going into hospital and they can stay up to a week. Since her child has become an adult, they've not had any support.

“They'd speak to us in a good patch, but then we'd have 8 months of constant crisis, no one has helped us with any respite.' There needs to be somewhere in the assessment where they are looked at in a good time and times of crisis.”

She was not told that they could have a review or another assessment and there's no where she could find information about what help was available.

### Design ideas

People felt they would need at least 5-6 hours to be able to do something that genuinely allows them to de-stress, this might be via day care.

“We used to get a carer in once a month, they would have a sleepover so my husband and I could go out, have a drink etc. For one night a week we didn't have to wake up. We took it in turns at night time but every now and then she would need two of us to tend to her. Once a year, we were able to put her in full time care for a week, that's what good looks like...carrying on the normal things we can do as a family. We don't see this anymore.”

## Third Phase Workshop with Stakeholders and Carers

For this stakeholder workshop we wanted to explore further the top four issues and ideas on what good looks like. The ideas, in order of priority for workshop attendees were:

1. Information on services, conditions and raising awareness for those who may not see themselves as carers
2. Access to and continuity of practical support for carers and their wellbeing. Proactive paid staff and peer support to help carers navigate the system and the support available to them
3. Carers Assessments
4. Working with professionals and communication

We invited a range of providers, commissioners and health and social colleagues, as well as the carers that had been involved in the previous workshops. 22 people (a mix of both carers and stakeholders) attended.

Prior to the workshop we shared summaries of the findings what seemed the four issues that seemed to have the highest priority for carers.

Below are the summaries provided as well as additional insights from the stakeholder workshop. The full notes can be seen in Appendix 2. Suggestions for the service specification are provided for each priority.



## 1. Information on services, conditions and raising awareness for those who may not see themselves as carers

Almost everyone had experienced difficulties getting information about:

- Mental health conditions and what to expect
- Support services for carers and where to find them
- Carers entitlements such as support services and benefits

### Design ideas

- It would be helpful that when you appear to a service, someone takes responsibility for giving you information to know what's available to you, offer a follow up to see how things are going, and talk about what are the next steps.
- Carers Information Packs should be revived and more easily available.
- The same information should be available via a single point of access and in the range of formats and online/offline.
- A single phone line is needed.

### Under 18s

- One stop shop to be brought into schools, a support system in schools would be a huge step.
- The term 'carer' should probably not be used with under 18s as those caring for children would probably describe themselves as parents or guardians.

### Further insights from the session

- Professionals need to recognise that any parent is a carer, they need to automatically provide them with information and support from the beginning.
- Services always seem to have boundaries and they send you to all different agencies. No one seems to co-ordinate it and there is no central point. Would be great to have a one stop shop for information and access.
- A 'carers passport' would be useful with info and next steps
- Information needs to be clear and concise as carers already have so much going on
- Ways to get information from other carers needs to be included
- Information needs to be online, video also with bitesize clips and information
- Be clear about the pathway and next steps

- The label of carer is not positive and can be stigmatising, better to help people recognise that they are in a caring situation rather than ask 'Are you a carer?'
- Professionals should help identify if someone needs support, without calling them a carer.
- Info should try to plant and early seed that the carers may need support – it can take time to come to terms with this
- Need to think carefully about how to distribute
- The information pack is good but dangerous without communications. If someone is alarmed by what they read or have more questions, then where do they go for help?
- A central repository of all services available should be made available like a map of services
- Important to have comms in points where carers could be identified – workforce, hospitals, GPs etc and in language that's not just carer for those that don't think of themselves as a carer.

### Service Specification Suggestions

- Information needs to be geared to a range of audiences:
  - People who would describe themselves as carers
  - Parents
  - People who may not recognise they are carers; spouse, family member etc
- One stop shop approach, online, telephone and linked to hubs and support groups
- Anyone identifying themselves or someone else as a carer needs to find the information easily.
- Information should be in bite size chunks, written, online and video formats.
- The information should clearly describe pathways and what carers should expect.
- The information should also describe entitlements and how to access them.
- Requesting information should trigger a carers assessment and contact from a carers support worker to offer support and explanation of the information.

- Promotion of the information available should be targeted where new carers would see it.
- Professionals need to take responsibility and be trained in identifying carers and referring them.

## 2. Access to and continuity of practical support for carers and their wellbeing. Proactive paid staff and peer support to help carers navigate the system and the support available to them

Carers spoke about the challenges of having workers assigned to them who then change or disappear altogether. Carers did not want to have to keep repeating their story.

### Design ideas

- All agreed it would be beneficial to have one case worker assigned to a carer at the beginning of the process, to touch base monthly and to provide different information at the different stages. Even if workers change, carers should be on a database that identifies they need follow ups, not leaving it to the carer to make contact.

### Under 18s

- In addition, there needs to be a support mechanism in primary and secondary school, either a worker or a peer support group.

### Further insights from the session

- When discharged from CAMHS felt like going off a cliff into black hole and there was absolutely nothing. Continuity for the carer is needed. Once a carer is registered as a carer, they should have a continuous point of contact and if this person leaves then they should be handed over directly to someone else. Carers need continuous support.
- It is a challenge if the patient is refusing help, but the carer wants the help and information. This makes it difficult to support them
- Needs to be person centred, one size doesn't fit all
- A single member of staff is a challenge, but could be a team rather than an individual
- A single meeting to assess isn't sufficient, you need to build a relationship over time to see the support carers need
- Carers need to know they can access support even if the person they care for doesn't have a diagnosis
- The service needs to be proactive, a point of contact that checks in, a relationship, someone carers can call in crisis whilst maybe waiting for a referral – just to have someone to speak to regularly.

- Could go on the CAMHS checklist to make sure the parents/guardians are somehow flagged up and someone contacts them with regards to being a carer.
- Support workers should be able to recognise if a carer is having difficulties and speak with them about support
- Used Surrey and Borders Point of crisis last night – they were excellent. Someone on the phone to speak to, someone who took time and someone who clearly gave instructions – do step 1, step 2, step 3. It was a calming and not overwhelming experience even though the person I cared for was in crisis hence the call
- Need for carer to have 24/7 point of contact
- Surrey Heath already have cancer navigators which work well then need to be well trained and the service needs to run smoothly so as not to cause more distress.
- Would be useful when person finds a service to know what is immediately available for them and plan for crisis – to include in service spec now and future planning not just immediate need.
- A carer on the call gave a best practice example that they had experienced (albeit some time ago) they had a care coordinator that was 'invaluable' to her as a carer, she provided updates when her child was in hospital check in that she was ok after crisis, regularly checked she was ok and became a TRUSTED extension of the care group for her child
- Care coordinators are in Primary Care sitting in PCNs where would the carer coordinator sit and whatever goes in the service specification should sit well with what's happening already not duplicate or conflict
- Not all carers can access carers hubs them as they can't leave the person that they care for. Numbers are low because of this. This was a model that was tried in 2014 and it didn't work then. AFC are trying to make them more accessible to more carers but lack of staff is an issue due to the cuts. They are still trying to offer 1:1 support at home but again, staffing levels are a problem.
- Action for carers is running specialist courses for carers, one about caring for someone with MH issues and another for carers of autistic people. Hoping that carers will gain a better understanding of the condition and how their loved ones feel and why they behave/react as they do. Gives a baseline understanding.
- One carer found an 'understanding autism course' herself which was a free Government one. No one told her about it. So beneficial although it is time consuming.

- Before section 17 CPA's worked in the MH teams and ran the training and educating around carers. Now back in the council and this has been lost.
- Crossroads Care acknowledged that some staff needed more training around giving breaks to people who have MH issues. There is still a stigma around this that they will be more difficult and also assumptions and perceptions about autism/ADHD – they are just naughty children.
- Action for carers lost the ability to offer specialist groups and call backs due to the contract changing. Lack of staff and time means they can no longer offer this service. Carers need this support and security net. Somebody who knows them and what's going on. They can check in as and when. No time limit on the help. Not having to repeat their story is a big thing. It can be very traumatic to keep talking about distressing incidents.
- Peer support? Depends on the person. In groups there are so many different personalities/perspectives. Sometimes the loudest person gets heard and there can be a lot of personal outpourings that can be upsetting/triggering for others in the group. It needs a trained person to either facilitate these groups or offer the 1:1 support.

### Service Specification Suggestions

- The support service should be integrated with information for carers, carers assessments and hubs/support groups.
- When carers have a referral, they should be recorded in a database that all support workers can access.
- There should be a consistent support worker wherever possible, but if not all support workers must have access to all relevant information about the carer to ensure continuity of support.
- Carers should be contacted regularly, the service should not rely on carers getting in contact for support. The service should aim to build a relationship with the carer.
- The support should be holistic, if they cannot help directly, they should refer and signpost to the right support, and follow up how this went.
- The support should help carers navigate pathways and help them to have plans in place for a crisis.
- If possible, the carers support should have close links with mental health services in case the person cared for is not sharing information on their treatment with their carer.



- The support must ensure carers have the information they need, support them to understand it help promote the information in the community.
- For parent carers, the support service should be embedded in schools and work with them to offer information, assessments and peer support.

### 3. Carers Assessments

Less than half of the carers we spoke to in the workshops had had a carers assessment, almost none of those who cared for someone under 18yrs had been offered one.

Those that had had carers assessments had not found them very effective, describing them as too many tick boxes and not giving the opportunity to talk about things truly impacting the carer.

The financial assessment was also a sensitive area, but more about how carers were left feeling rather than any objection to having to pay for services.

#### Design ideas

- The carers assessment needs to have less tick boxes and be more of a discussion and wide ranging assessment of the carers situation. This will open up opportunities where carers can be supported more widely with relevant information and signposting.
- This could also help people to feel they are still being directed to free support, even if they have to pay for some services.
- Better sharing of the carers assessment needs to be explored to reduce the need for carers to retell their story.

#### Further insights from the session

- There is not enough support as they aren't seeing you as a whole person.  
*"I am also a human being, I'd like to have my own life, I'm unable to have a job just stuck trying to navigate the system."*
- Requesting an assessment can be a confusing system to navigate
- Professional need to have awareness of signposting routes for carers assessments
- Services think they're helping you parent rather than being a carer to a child using MH services – that needs to be explained and the carers assessment process needs to be built in
- Recognising different needs and the right support as early as possible is vital
- What are the alternative routes for support if you don't meet the threshold for all carers services?
- Being re-referred is difficult, especially in crisis. You have to wait for a referral, it'll be useful to know where to go. A carers assessment could provide this information.

- Carers assessments where cared for person is under 18 could include information on breaks, respite for the carer, practical support at home, someone to build a relationship with that the anxious child would be comfortable with.
- An annual review is needed
- Face to face or online, depending on the persons needs
- Action for Carers have given a good service, as soon as registered online as a carer with GP, Action for Carers got in touch. This hasn't happened with CAMHS.
- Quality of the outcome of the assessment vital
- Negativity around what a carers assessment actually is. Didn't understand what a carers assessment was. Feels quite invasive and like being under the spotlight. Perception was that it was going to be like being judged.
- Need to emphasise the benefits of the assessment – as majority of carers don't see the value
- Lots of people think its just financial support so don't follow up
- Person doing the assessment needs to be trained to understand the conditions and understand as different carers have different needs.
- Should be clear on next steps e.g. if you are eligible X will happen if not eligible then X will happen
- Crossroads care – referred 330 for CA since 1<sup>st</sup> April.4 have heard back Why can't the refers be sent a courtesy email just to let them know that it's been received. Apparently ASC don't do this – why not?
- Huge waiting list for CA to be carried out and discrepancy in how well they are carried out. Staff need proper training to do them. One practitioner admitted that she had googled how to do them as she didn't know how to!
- Practitioner should ask 'are you willing and able to continue in your caring role'
- Now MH CPA's and the locality CPA'S ( ASC) are under the same umbrella. Each area has 1 for locality (ASC) and 1 for MH. It was sporadic before.MH CPA's will do a CA in depth if there is a conflict of interests. Ideally they should be supporting the locality CPA to do the assessment. It is a LEGAL requirement which they shouldn't be dodging/avoiding/doing badly.

### **Service Specification Suggestions**

- The information needs to be clear what the carers assessment is, how it will be carried out and the possible outcomes.

- Training for staff to carry out carers assessments and be sensitive to the stigma and exposure carers may feel during the assessment
- The assessment needs to set out clear pathways and next steps for the carer
- Carers must be told they can ask for a review if their circumstances change
- The carers assessment is a live document that should move with the situation and be referred to regularly.

## 4. Working with professionals and communication

Carers described significant challenges with the way mental capacity and privacy were managed by professionals, often leading to them feeling excluded from discussions about the care of the person they care for.

Attendees wanted professionals who understood the relevant pathway to share information on the pathway with them, understanding what to expect next was very important.

Attendees raised particularly challenging times are during crises and when the person they care for is in mental health inpatient services. They also commented on how communication from professionals reduces significantly once the person they care for is 18yrs.

### Design ideas

- Having someone outside of the professionals but aligned with them would be helpful.
- Re-establish the Triangle of Care model across all services.

### Further insights from the session

- One carer said this topic was the hardest thing to deal with as a carer the inability to communicate or get information from the professionals involved in the care of her son
- Hospitals even with permission to talk to parent from child – say they need permission which stalls them, made to feel like nuisance when ringing for updates – encouraged to not contact rather than stay in touch – should let parents/carers know what to expect, best time to call, where to get information not made to feel like a pain
- Teams can be overworked and overwhelmed – carers are having to research the right people to copy in emails just to get a response and shouldn't have to do that.
- Being re-referred is difficult, especially in crisis. You have to wait for a referral, it'll be useful to know where to go. A carers assessment could provide this information.
- In schools it feels like one size should fit all, 'every parent is trying to undermine the school', and the system, isn't doing their job properly. Parents feel like they are being told how to do their job and aren't doing enough.
- No awareness of triangle of care.

- Expectation of services from the beginning, when should the communication happen, should there be an action plan at the beginning – action plan on the steps and the pathway would be brilliant to understand the process.
- Conflict between professionals and school staff, led to being pro-active and 'googling'.
- Being excluded from conversations from professionals has led to crisis
- Needed someone outside of the structures that I could go to
- Consistency. You never know which professional it would be each visit
- Independent body outside of the situation
- Proper trained individuals, trained in mental health. Empower professionals to be fully trained and as knowledgeable as possible before entering a family home or a new situation with a new individual
- The carer in the group said this works better in other areas and her son was sectioned out of area it was a different experience, the consultant rang and explained – never had a consultant ring in Surrey.
- Need staff with specialist knowledge and training to deal with autism and neuro diverse people. You have to take a completely different approach with them. They must be trained to work with people who can't engage.
- LD and autism teams don't work together.

### Service Specification Suggestions

- The support service needs to support the re-establishment of the Triangle of Care model and help carers advocate for the statutory rights to be involved.
- The support service needs to assist carers with getting in contact with the right professional at the right time, and help them escalate when they are not getting a response.
- For parent carers, the support service needs to work with schools and with CAMHS to support carers to advocate for their child.
- The support service staff and volunteers need to have appropriate training in mental health, autism and neurodiversity.

### Other insights and Issues

More joined up information when children transition into adult services.

Carers felt alone if their child or cared for person wasn't accepting professional help.





## Appendix 1

### Designing support services for carers of people using mental health support

30<sup>th</sup> May – 2 – 4pm via Zoom

#### Discussion points

- Carers breaks
- Support for carers working with professionals and need help getting responses or need navigation support
- Training for staff
- Access to and continuity of practical support for carers and their wellbeing
- Proactive paid staff and peer support
- Navigation for new/current diagnoses
- Information on conditions and raising awareness for those who may not see themselves as carers
- Space for carers to share their experiences with others

#### Feedback

- The conversation started with a lady whose Mum has Alzheimer's Dementia. Early on she was lucky to get respite care one afternoon a week from Crossroads Care which was paid for by Surrey County Council (SCC). Lovely service, had the same carer for about 2 years, but at the beginning of April she was told that SCC had changed the way the service operates and they could only have 35 hours a year of support. That became an issue. 'I feel lucky because Crossroads have a waiting list which lots of people are waiting for'. There are bigger issues and Action for Carers (AfC) have told her to make a formal complaint to Healthwatch Surrey. Social services will have to assess their needs before she can tell what will happen next. 'They were condescending, almost as if we should be grateful we've got anything, this wound us up'. She mentioned that they'll make their own arrangements which they'll have to pay for. They have attended a few of these carers

groups in the past couple of years regarding Surrey services wanting to improve their service levels, but she explained that she feels the system is playing politics. One afternoon 3.5 hrs a week wasn't enough, so she recently got her Mum into a day-care centre which they pay for 5.5 hours a week. 'That feels enough, I can actually enjoy some time to do what I want. We have made our own choices, I'm not going to demand from the NHS or Social Care Services what I want'. Crossroads offered a paid for service to extend the time her Mum was at the day-care centre.

- A lady, whose son and daughter-in-law, both with bipolar disorder are working but have times of distress. It depends on how well they are supported, if they're supported then you can have a break and peace of mind. Her Mum has also had a stroke (dementia related) and is a wheelchair user and she can't do anything for herself, this involved practical help in the home and physical tasks of caring. Her support was done by a carers assessment, 'how can you line people up for crossroads without any indication on the challenges they're facing in their everyday life'. She was recognised as a working carer and she was given support which worked alongside this. 'We used to get a carer in once a month, they would have a sleepover so my husband and I could go out, have a drink etc. For one night a week we didn't have to wake up. We took it in turns at night time but every now and then she would need two of us to tend to her. Once a year, we were able to put her in full time care for a week, that's what good looks like...carrying on the normal things we can do as a family. We don't see this anymore.'
- Another lady expressed gratitude to a programme called Hope, which was respite care for young people. It is a place for them to go instead of going into hospital and they can stay up to a week. Since her child has become an adult, they've not had any support. 'They'd speak to us in a good patch, but then we'd have 8 months

of constant crisis, no one has helped us with any respite.’ There needs to be somewhere in the assessment where they are looked at in a good time and times of crisis’. She was not told that they could have a review or another assessment and there’s no where she could find information about what help was available.

- The fourth lady explained that she had not received a break, but when her son took his own life, she was given £300 by SILC which she explained ‘felt like an insult’. She didn’t need respite because her son does not live with her. ‘The assessment is too general, a lot doesn’t apply to a lot of carers, that’s the thing, it can’t be personalised, it’s too much of a tick box thing, we’re one of thousands’. She explained that within the assessment, the conversation was based heavily on money and how many days a week she cares. She went on to say that it is hard to justify, one week they may be okay and the next they are in crisis, you can’t ask for an assessment every week.
- Many felt in constant worry all the time, fearing the worst.
- Carers end up taking medication themselves for this worry.
- A lady whose husband is using mental health services, spoke about her assessment where a case worker was assigned to them but then he disappeared with no replacement. She doesn’t have a connection with SCC, but all the communication she does have with them is about her husband. She would appreciate more carers communication directed to her and to be told what support was on offer for her.
- Having someone outside of these professionals, for example, family therapy or talking therapies would be useful.
- Mobilise – and other services – ‘how are we supposed to know about these without doing our own research?’
- Lack of information on the SABP website under carer. It would be useful to have a map of the services and support in the area. This would especially be helpful for when you’re new to being a carer.

- “Due to many things, like changing of staff, information and communication just seems to go missing. Systems keep changing, that’s the main problem!”
- “The system sees you, but they don’t see you as a person”
- The Dementia diagnosis process was different to the experiences of those who went through the mental health process. Dementia was more structured, ‘I felt overwhelmed by the information available to me, it was clear to me what options I had available.’
- Dementia navigator isn’t useful – they don’t recognise her (client) as a person.
- Heard a positive story around social prescribing – ‘My GP put me in touch with the social prescribing team, I have been speaking to a lady who is fab. She seems to know and have answers for everything I throw at her.’
- The frailty hub also received some positive feedback – ‘The frailty hub was great. I felt like I was on my own, I had too little support and now I know where this support is. It has been a godsend. There should be hubs for everyone. Knowing they are there has taken a weight off of my mind and less stressed.’
- There was a conversation around the triangle of care – where has this gone? – Due to staffing, not a lot has happened, but it is going to hopefully resume soon.
- Be good to have someone to offload too and to make them aware of the situation in times of crisis.
- I have my sons reference number which I can use to make a referral which is peace of mind, but it will still be nice to have someone to speak to.
- ‘AfC are very helpful, but it’s a long process to get to someone who can help.’
- There was a mutual need from the group that they would appreciate someone to go to for support. They explained difficulty getting hold

of people and getting them involved at the right times. There was a lot of uncertainty with who you can speak to; who is your contact person when you've got a query?

- One of the ladies mentioned that when she was new to using the service, she had no idea where to go for support. There was a lack of information on the SABP website, and the information that was on there was out of date.
- Working hours of services needs to be clearer so people know who to contact and when.
- Safe Haven is useful, however it'll be useful to have somewhere to go when they are closed.
- Two of the ladies spoke about the lack of mental health inpatient services, especially in discharge where lots can go wrong. 'There is a lack of staff to go too. There needs to be equality in this service when compared to the others. It's discrimination to mental health carers. They tell you to speak to PALS but it takes a 2-day turnaround which isn't good in a crisis. There's nowhere to go and you hit a blank wall.'
- A specific case from one of the group saw her son being sectioned. The first time he escaped, she warned the staff of this, however he managed to escape for the second time – 'It just feels no one took notice of what I said. There needs to be someone that believes the carers when they say something.'
- Information provided by different trusts are worlds apart.
- There was a mention of needing to train staff better – 'Some services deal with my mother who has dementia directly, but she doesn't always know what's going on. They asked her to sign a document to agree to the procedure rather than me, but she had no legal capacity to sign it.'
- A lot of learnings have been lost during covid.
- The conversation turned to peer support, there was a mutual need for peer support, whether from a family member, friend or people that are going through the same situation. The majority of the group were aware and have attended support groups (from their own

research) but one lady hasn't attended any groups and wasn't sure where to find them.

- One lady used to attend an AfC support group in Reigate, but it wasn't well supported. Many services seem to be based in Guildford, would prefer services a bit more local.
- There was also a need for specific support groups rather than general ones, face to face was preferrable.
- Different to the above, one lady mentioned that she finds attending the dementia support group difficult and can only attend when she is in the right frame of mind – 'hearing everyone else's problems makes me feel worse.'
- Groups need to be available at all times of the day.
- The group discussed the main things they wanted to see budget put into:
  - Good information on what is available
  - Having a key contact for support and continuity.
- Navigators are important. Get rid of inequality in inpatient care – carers often feel conflict with health practitioners.
- Family approach is vital.

Designing support services for carers of people using mental health support

31st May – 10am – 12pm via Zoom

**Discussion points**

- Carers breaks
- Support for carers working with professionals and need help getting responses or need navigation support
- Training for staff
- Access to and continuity of practical support for carers and their wellbeing
- Proactive paid staff and peer support
- Navigation for new/current diagnoses
- Information on conditions and raising awareness for those who may not see themselves as carers
- Space for carers to share their experiences with others

**Feedback**

- Difficult to communicate with CAMHS, “there’s no signposting and I would have no idea where to go for support or for a break” – haven’t received a carers assessment. Although she has not received a carers assessment, both children have had targeted youth workers, but they haven’t really worked with them. “It’s about having the time, and having the support through the process’s, I have to go through PALS to get a response from CAMHS for support. It’s a full time job in itself having to do that”.
- The other 2 attendees have not had a carers assessment.
- Carers presence or availability to be monitored more efficiently, so they know when the carers are away. The care and communication is inconsistent, just having that system in place would make it feel like a break. More clarity and structure to what is available.
- There was discussion that you had to be proactive to find the support you needed, but finding the right group can be hard.
- Lack of support for parents, always feeling they’re to blame.



- Praise for AfC
- Tick boxing was mentioned a lot throughout the session “There’s a lot of tick boxing and not an awful lot of doing.”
- When children transfer into adult care, no one seems to consult the parents anymore.
- “It’s hard to get some support and understanding when your daughter doesn’t present in a public setting. I can tell them what’s happening at home, but unless I get evidence of this they just offer mindfulness and meditation.”
- One of the ladies children were assessed for ASD and she was given a 30 page document which went through what was wrong. This document included a page with further support but there was no structure to what she was given, it was a case of ‘there you go, the rest is up to you’. All she found out was via Facebook groups, and recommendations. ‘I’ve had to learn about this, this is what takes up my time, and no one has ever checked up on me, it’s been incredibly tough’.
- It would be helpful that when you appear to a service, it’ll be useful to know what’s available to you and a follow up. Someone reaching out to see how things are going, what are the next steps.
- When you get the information, the problem then moves into communication.
- Communication to the carer isn’t always there, they communicate with the person with the diagnosis but not us, so they rely on the person communicating with the carer to know what’s going on. When the services want to speak to the patients they’ll be there, but when they don’t it isn’t easy to get hold of them.
- “You’re effectively told parenting is the issue why your kids won’t go into school. The pressure this puts onto you as a parent, broke me.”
- “The effect of what is there and how people communicate is important too, when your child is diagnosed, there’s a period of grief you go through, you’ve lost the child and the

future they thought they'd have. I don't think this is recognised at all. No support around the mental and emotional impact."

- There was conversation around the community mental health teams and the lack of staffing. One lady had a positive experience where she as the carer was the priority, and they would meet every 6 weeks, but the support would be there as and when she needed it. "I didn't have to explain things, she already knew, and you could be honest and she not only came back with emotional support, but practical support too, I managed to have some counselling. There was a trust, that was the nicest thing, we could speak to her and she would keep us updated. Now she's gone, there's a real gap."
- Having a specific point of contact so you didn't have to repeat the story all over again would be beneficial.
- "We need to be heard, it's just a nightmare with the system. Frightening".
- Want to be listened to as an individual, but the shared experience isn't coming through. If this experience is happening to a lot to people then it's not working right.
- There was a lack of staffing with CAMHS too – one lady's daughter had no idea who her case worker was or what they're supposed to do. She's currently on her third case worker because they keep leaving. "I've had times when she's suicidal, I'll email because it's quicker to get a response, and I copy the lead in on everything because it's the only way I get a response. I get asked is she likely to commit suicide, am I qualified to answer this?" There numbers you can call but you need someone there to talk too.
- Lack of support from the system causes more pressure on paramedics and hospitals.
- WhatsApp and Facebook groups provide support and signposting from other people in the same situation.

- Even more support needed for children post covid who are finding it hard.
- Knowing which groups are suitable to you would be useful and will save time. Having guest speakers so you can learn would be even better.
- Staff not using jargon – the carers needs to understand.
- Praise for Family Voice.
- “People that know what you’re going through are the best people to be around. Parents need a single point of access.”
- One stop shop to be bought into schools, be incredible if the school has a support system.
- Hard to get your loved one to understand the constant changing of procedures and staff. When people are changed last minute, it effects the way they feel.
- ‘A carer should be a partner too, we are an equal partner in that care’.
- It isn’t AFC it’s ACS – I think that was who Ros mentioned them.
- Carers don’t want to keep repeating themselves
- SABP – carers would like to know what the composition of the MH teams. Who’s who
- Carers packs
- Their loved ones should know about changes otherwise they feel that they are just being ‘done to’. This in turn makes them feel like they don’t matter which doesn’t help their MH.
- Specialist speakers to help carers understand conditions

Designing support services for carers of people using mental  
health support

1<sup>st</sup> June – 6 – 8pm via Zoom

**Discussion points**

- Carers breaks
- Support for carers working with professionals and need help getting responses or need navigation support
- Training for staff
- Access to and continuity of practical support for carers and their wellbeing
- Proactive paid staff and peer support
- Navigation for new/current diagnoses
- Information on conditions and raising awareness for those who may not see themselves as carers
- Space for carers to share their experiences with others

**Feedback**

The people within this group all had children with mental ill health.

- One lady has not received a carers assessment, even though she has been having visits for years. She did ask for a carers assessment yet this was refused and was told 'it wasn't part of our job'. All of the services are very limited, they don't really know what other services/people do, "it's like they live in a box, they don't know what the other people do and there is no coordination and networking so that is left to me, the carer."
- Down to the carer to research what services their children should be receiving and how they can access these.
- Parents act as a social worker, yet don't get paid, don't have access to resources, no knowledge of what's available and in the dark all the time.
- One ladies Son has lost his confidence due to not attending School. He was supposed to have his EHCP looked at legally over a year ago, and with that year he's been sat at home, hardly going out and he's now lost his social skills, confidence and now his mental health has

been impacted. He should have had support from services coming into the home which has not happened. This would have helped the carer massively.

- HCP is the hub of all services, if this isn't set up on time, you do not have access to all these resources.
- These parents have become members of many organisations to keep up to date.
- Carers mental health is hugely impacted due to the lack of support.
- They have not received help with various documents including legal documents, which need to be handled carefully often have no one to help go through it. **"It's so confusing, there's no one there."**
- Family Voice Surrey was mentioned as a form of support to one lady, who were outraged when they heard how they had been treated her and her son. The CEO ended up helping her write an email to correct the issue.
- Continuously chasing people which is exhausting to carers. **"Hard to spend all your time on emails and on the phone, when you're looking after someone who is poorly."**
- Some specific eating disorders don't get help from adult commissioning services, carers left on their own.
- **"Parents are seen as super social workers."**
- Lack of help, support and communication when the child transitions into adult services. Parents are not kept informed as their children are then classed as adults, and they then have to rely on their children to tell them about their care. Children can often hide things they don't want their parents to hear. **"It's extremely challenging, we don't know what's happening."**
- One lady who did have a carers assessment did not have a good experience. She never heard back after the carers assessment. She didn't know carers assessments were a thing until she stumbled on it. We need to know the different options that could help us and they are only finding out things by stumbling across it. **"Having more information would decrease the amount of times we have to call them!"**

- “You feel devalued.”
- “In an ideal world, as soon as your child is diagnosed, you’re assigned a case worker to support you and provide information. That would be hugely beneficial.”
- We can’t care for our loved one if we don’t have the information.
- It’ll be beneficial to have one case worker assigned to you at the beginning of the process, to touch base monthly and to provide different information at the different stages. “Having someone to check in on us would be fantastic. By giving us the information, we will know where to turn.”
- No one knows about claiming DLA – people could claim for years.
- Another lady’s son who also has mental ill health shared experience of having no help. No one listened to her and now her son has mental ill health from not receiving early intervention. He also has no communication or socialisation skills.
- There was conversation around the lack of support from schools. One lady’s son tried to kill himself and has not been back to school since. “These problems could be avoided if his symptoms were captured and us carers were supported earlier on.”
- “The School didn’t listen, if I had been heard when my son was 5, we wouldn’t be where we are now.” They would call when he was lashing out but they wouldn’t see what the issue was behind the scenes causing him to lash out.
- You shouldn’t have to wait for a diagnosis to get support.
- There was conversation around the lack of staff at CAMHS. One lady’s son got seen only because she kept pushing with the CEO at SABP and her son tried to take his own life. She also has not received a carers assessment. Even though her Son is under social care due to the suicide attempt at a young age, he’s classed as a child in need, yet they haven’t offered the family any help. “I’ll have to give up work and be my son’s full time carer and I’ve mentioned this to social care and I’ve got nothing. It’s exhausting, I have now ended up with depression. How can you as one

person, be a partner, be a mum, carer, social worker, psychiatrist, run a home and have a job, as a human being you're going to break at some point, and then who's going to look after your child?"

- There is a massive gap with education and early intervention, and this was backed up by the group.
- A lot of the carers are a part of WhatsApp groups, Facebook groups, and carers groups and some even taking training to understand what help they can get. All of the group reiterated how they do their own research for everything, it's just down to them. "It's great to hear the experiences of other people."
- Professionals know what the pathway is, why aren't they providing people with this information?
- There was another mention of different information being provided at different stages would be useful. This information also needs to be provided at the right times.
- Carers need to be identified.
- There was conversation around carers packs and where they've gone. Lisa Roberts is looking into this.
- Looking at the connection between genetics and diagnosis. Lots of parents may also have a diagnosis so information provided in a way they understand is important. Do they need an advocate? Are they struggling themselves? Is the parent capable of doing this role? Do they have help? This is what the cares assessment should do.
- Carers not even knowing their carers – more information needs to be provided.
- Carers assessments need to be put out there more and the child and parent should be seen equally. The responsibility with clinicians should be that they have 2 patients.
- Packs should be given immediately and provided printed, verbally and visually. You Tube videos? More accessible.
- A helpline – specific for parents of young people with mental health issues.

- “The schools can see you’re struggling, they can see the child needs help but they don’t want to get involved.” Early intervention...
- More hands on training for carers.
- Carers not wanting to repeat themselves to everyone who walks through the door. Need one person who knows everything.
- Carers feeling of failure, affecting their own mental health. “I don’t know how to support him anymore. What we really need is consistent professional treatment/support for struggling ill children.”
- There was conversation around the staff that you see and it being ‘chance who walks through your door to the support you get’.
- More enthusiasm for early intervention, early referrals and for the process to start in early school years. EHCP to happen early.
- More observation, meetings with the parents at school. Parents aren’t listened too by the school. It’s almost like they don’t believe you.
- One lady mentioned she then began to feel like she was the problem so stopped chasing as much.
- Peer support is fabulous for knowing we aren’t alone, but it shouldn’t be relied on for signposting.
- The early help needs to be appropriate effective therapeutic help not just comfort.
- Professionals with lived experience would be beneficial, “they can see what position you’re in and what support you can get at that stage. They can hold your hand through the process, refer you to groups, help attend meetings for support”, would be very helpful. Like a buddy scheme (fantastic idea from the whole group). Shouldn’t be a replacement to other staff.
- Consistency in a specific skillset based on understanding the needs of the family.
- Recommending mindfulness and meditation is insulting.
- Covid has really had an impact on services but these need to get back to normal



- “The brain doesn't stop developing until the age of 25, I think that as parents, we should have shared information until that age.”
- Family's need someone to come into the family and look at the whole family. Being a carer puts a huge stress on all the relationships within the family.
- Online support groups are cheaper and still effective, don't have to be battling to get somewhere. Zoom much easier when you are dealing with kids needing 24/7 supervision.
- Relying on attending support groups for emotional and practical support.
- National Autistic Society have been amazing.
- Support face to face but with someone coming into your home 100%, having that option would be good.
- Parent carers often don't talk to their friends if their children does not have mental health problems, because they don't understand what it is like.
- “Before they set up support groups, please could they check what already exists. I'd rather they put the energy into things that don't exist and are needed. If there are groups that exist then signposting to them might be what's needed.”
- Linklight – an organisation based in Farnborough puts together a list of support groups in their area. Maybe all areas need this?
- Does the council realise there's lots of unidentified carers?

Facilitator to attend support groups are very, very helpful. They can put you in touch with the right people and help you

## Appendix 2

### Designing support services for carers of people using mental health support

Stakeholder Workshop 29<sup>th</sup> June 2022

#### Notes from Group 1

#### **1. Information on services, conditions and raising awareness for those who may not see themselves as carers**

- CAMHS
  - need to recognise parents as carers
  - need to provide more information in general
  - there is a gap between CAMHS and Adult Social Care (ASC)
- Recognition as a carer.
- Professionals need to recognise that any parent is a carer, they need to automatically provide them with information and support from the beginning.
- Doctor has provided useful information, but it is hard to get an appointment.
- Struggle with not meeting the threshold to receive support. But they could see you on a good day, they aren't there every day and to see you when your in crisis.
- Useful to have a one-stop shop for information
- Services to be more efficient in conversations they have at the beginning
- Carers passport – handy steps and bites of information for carers.
- Information needs to be clear and concise as you already have so much going on.
- So much information has come from parents, not professionals.
- Video's, animation, small videos – accessible information for all.
- Clear pathway.
- Carer – it's not a positive label, it's more recognising yourself in that situation to relate too, that's a lot more powerful then calling themselves a carer.
- Having a professional notice someone needs support without calling them a carer, important to differentiate.

- Continuity when transitioning through diagnosis

## **2. Access to and continuity of practical support for carers and their wellbeing. Proactive paid staff and peer support to help carers navigate the system and the support available to them**

- It is a challenge if the patient is refusing help, but the carer wants the help and information. This makes it difficult to support them.
- Multiple different scenarios for different conditions, there isn't one solution to everything.
- Really needs to be person centred.
- Difficult in the constant staff changes, a team more than an individual person. A helpline rather than an individual person.
- More staff training and awareness to different conditions.
- Being assessed on one day isn't good enough, a relationship needs to be built to really see the support you need.
- **"It's like a 1000 piece jigsaw puzzle that's been mixed with someone else's puzzle that's impossible to put together."**
- Without a diagnosis, where do you fit in? Where do you go?
- Issue with being out of the system, unless your GP is switched on it can be variable the support and information you get.
- Do the primary places have the correct information available? Do they have correct training?
- Teams can be overworked and overwhelmed – having to research the right people to copy in emails just to get a response – shouldn't have to do that.
- Needs to be accessible – proactive from services.
- Parents and carers want information in the right time.
- ASC – seeing someone weekly, if I couldn't attend they reached out to check I was okay. This was brilliant.
- One size doesn't fit all – especially for children's mental health.

## **3. Carers Assessments**

- Should be offered!

- One parent carer filled out the form online to request an assessment, but realised this was for ASC. She soon realised this and followed a link on that page to request a carers assessment, but when she reached that webpage there was no information on how to access an assessment.
- Very confusing system to navigate.
- Children's services don't operate same as adults, there's no checklist with children, it's more about developmental changes, are they growing up to be healthy?
- Services think they're helping you parent rather than being a carer to a child using MH services – that needs to be explained – process needs to be built in.
- Do the professionals have an understanding?
- From the get go – being offered the correct support from your situation.
- Finding out if your eligible for a carers assessment, and if not, what other support can you get – people are put into different boxes, if you don't fit, where do you go?
- Recognising different needs.
- More joined up information when children transition into adult services.
- Being re-referred is difficult, especially in crisis. You have to wait for a referral, it'll be useful to know where to go. A carers assessment could provide this information.
- A point of contact that checks in, a relationship, someone you can call in crisis whilst maybe waiting for a referral – just to have someone to speak to regularly.
- Carers assessments – information on breaks, respite for the carer, practical support at home, someone to build a relationship with that the anxious child would be comfortable with.
- Carers assessments – annually? Check up's in between as there can be changes in diagnosis. Face to face and online is good, but depends on the persons needs.

#### **4 . Working with professionals and communication**

- Schools – one size fits all, 'every parent is trying to undermine the school', and the system, isn't doing their job properly. Parents being told how to do their job. School isn't the right place, so much pressure in general. Assumption as a parent you aren't doing enough.
- There is not enough support as they aren't seeing you as a whole person. "I am also a human being, I'd like to have my own life, I'm

unable to have a job just stuck trying to navigate the system.”

- Charitable organisations have been beneficial.
- Action for Carers have been great, as soon as I registered online as a carer with my GP, Action for Carers got in touch. This hasn't happened with CAMHS.
- No awareness of triangle of care.
- Expectation of services from the beginning, when should the communication happen, should there be an action plan at the beginning – action plan on the steps and the pathway would be brilliant to understand the process.
- Conflict between professionals and school staff, led to being pro-active and 'googling'.
- Being excluded from conversations from professionals has led to crisis, is this down to training?

**Notes copied from chat:**

I didn't get to mention that as carers we need tailormade/bespoke one-to-one training with greater depth knowledge/information.

There doesn't seem to be a connection between ANY of the services - Particularly with CAHMS.

Just briefly touched upon the organisation Newbold Hope in our breakout room - definitely worth consulting regarding their peer support for carers of children and young people with learning disabilities/neurodiversity/mental health conditions.

She is amazing, my first point of call when things got really tough, she made me see many things in a very different light.

She is amazing for staff training, too.

Sorry but not only are you dealing with neurodivergent children but it will be quite likely that parents may also be neurodivergent highlighting the importance of a better understanding even more so and professionals/support workers with the relevant skillset

Definitely need services to continue support even when child doesn't engage. Unfortunately a lot of help is only available when crisis is hit and then it's too little too late.

Agreed - if the child doesn't engage... there's no help. If the child is not engaging - then whatever the professional is doing isn't working and there needs to be a change of direction.

100% - my 12 year old son won't engage now he has hit crisis point - all down to lack of early intervention and us as carers not being heard by professionals much earlier on.

Same here! My Daughter sat under the radar outside of the home so all down to me to keep asking. She has now shut down and barely leaves her bedroom.

It's so difficult Ross and I hope that with time her brain will develop and that this situation will improve for you all.

Surrey has a new Advocacy service for Children starting in July 22 being managed by a company called Antser Holdings.

## Notes from Group 2

### Question 1

- Feedback from parent carer – Had no idea she was a carer. Lack of early intervention. Should start at nurse. There should be support/advice from schools as early as possible. Made to feel you're a bad parent.
- All info should be accessible for everyone. One size doesn't fit all. Info for neuro diverse parents.
- Action for carers have carers hubs running through out the county. However not all carers can access them as they can't leave the person that they care for. Numbers are low because of this. This was a model that was tried in 2014 and it didn't work then. AFC are trying to make them more accessible to more carers but lack of staff is an issue due to the cuts. They are still trying to offer 1:1 support at home but again, staffing levels are a problem.
- Feedback from carer of adult with both MH and physical issues – support for MH isn't there. Went into field of work to find out what was there and improve things for carers. Men who are caring for someone with MH issues are especially hard to engage with/identify as carers – don't see themselves as such. Just get on with it.
- Training and more information from specialists about what's happening to the cared for person. Then they can cope with difficult times/situations/scenarios as they can approach from a different , informed angle.
- Action for carers is running specialist courses for carers, one about caring for someone with MH issues and another for carers of autistic people. Hoping that carers will gain a better understanding of the condition and

how their loved ones feel and why they behave/react as they do. Gives a baseline understanding.

- One carer found an 'understanding autism course' herself which was a free Government one. No one told her about it. So beneficial although it is time consuming.
- Before section 17 CPA's worked in the MH teams and ran the training and educating around carers. Now back in the council and this has been lost.
- Crossroads Care acknowledged that some staff needed more training around giving breaks to people who have MH issues. There is still a stigma around this that they will be more difficult and also assumptions and perceptions about autism/ADHD – they are just naughty children. Staff need training to develop the skills, confidence and understanding needed. All staff should have training Mentioned Oliver Mc Gowan project.
- Carers breaks currently capped under the new contract at 35 hours. With someone with MH/neuro diverse issues, this isn't enough time to build trust, rapport and build a relationship. Should be longer.
- What's in a word? Maybe call them a care giver or ask ' do you support someone who couldn't manage without you? ' The words/language you use as a professional are important in getting a person to identify as a carer. Think about them carefully.

## **Question 2**

- Action for carers lost the ability to offer specialist groups and call backs due to the contract changing. Lack of staff and time means they can no longer offer this service .Carers need this support and security net. Somebody who knows them and what's going on. They can check in as and when. No time limit on the help. Not having to repeat their story is a big thing. It can be very traumatic to keep talking about distressing incidents.
- Parent carer feedback – big thank you to Barbara at AFC. Amazing. Checks in and sent a voucher for the family to enjoy a meal out together. Made such a difference. Carer has recommended AFC to friends who didn't know about the organisation. She didn't know about them until crisis hit. Barbara has supported the family at TAF and CIN meetings. It's this 1;1 consistency that carers need. Sometimes they need to offload and have a cry and they need to do this with someone who is properly trained and resilient enough to cope with their emotions.
- Crossroads Care – although they provide carers breaks they also end up supporting the carer too by listening to them.
- Peer support? Depends on the person. In groups there are so many different personalities/perspectives. Sometimes the loudest person gets heard and there can be a lot of personal outpourings that can be

upsetting/triggering for others in the group. It needs a trained person to either facilitate these groups or offer the 1:1 support. They can then open up the channels for the carers and listen. One person had an analogy for this. It's like having a back pack of emotions. If it gets too full the straps will break but if there is the ability to take things out sometimes, the straps won't break. Positives for peer support – hear things that then happen to you in the future and you are then prepared. You see others coming through things and they have survived!. Can make things not so scary.

- Carers need to know what services are out there and who to talk to
- There are different needs for those caring for someone with MH issues as opposed to physical issues.
- Carers need to take time for themselves and not feel guilty.
- Large online carers support groups – hard to make meaningful. 1:1 is SO important. Everyone needs time to offload and not in front of other carers. Not very confidential either. Large groups are particularly inappropriate and unsafe for young adults with MH issues. They can be scared by hearing some of the other people's stories. They then shut down and stop accessing support.
- Smaller groups are ok but they had to stop due to lack of staff ( again the new contract and funding)
- So much demand and not the capacity within organisations. Recruitment is a problem.

### **Question 3**

- Lack of knowledge about what they are/what they are for/how to access them/who carries them out/ what is the point of them? 'never heard of it' 'Don't know what it is' 'word assessment sounds like a test'
- Crossroads care – referred 330 for CA since 1<sup>st</sup> April.4 have heard back Why can't the refers be sent a courtesy email just to let them know that it's been received. Apparently ASC don't do this – why not? Carers then ring Crossroads to ask what's happening and they don't know. Bad communication. ASC then say they have no capacity to do the assessments ( even though they have a statutory obligation to do them if requested). There is no clear explanation or pathway to let people know what will happen once a referral has been made.
- Huge waiting list for CA to be carried out and discrepancy in how well they are carried out. Staff need proper training to do them. One practitioner admitted that she had googled how to do them as she didn't know how to!



- Should be explained to the carer that they are an acknowledgement of your caring role and the impact on your well being.
- What's in it for the carer? Possible funding/information/signposting/referral to AFC/recovery college/making them aware of what's around them. Also gives them the opportunity to speak openly ( without their loved one for present)about what they do in their caring role and how they honestly feel about it.
- Practitioner should ask 'are you willing and able to continue in your caring role'
- Now MH CPA's and the locality CPA'S ( ASC) are under the same umbrella. Each area has 1 for locality (ASC) and 1 for MH. It was sporadic before.MH CPA's will do a CA in depth if there is a conflict of interests. Ideally they should be supporting the locality CPA to do the assessment. It is a LEGAL requirement which they shouldn't be dodging/avoiding/doing badly.
- Data needs to be recorded accurately about how many assessments are being carried out, by whom and the outcomes.
- Ideally carers should be identified prior to assessment.
- Apparently SABP are getting rid of care coordinators – who is replacing them? What is the reasoning behind this?

### **In a nutshell for CA**

- Training for staff
- Clear pathways
- What will the carer gain from a CA
- Identification of carers who haven't asked for help
- Carers told they can ask for a review if their circumstances change
- The support they are signposted/directed to is relatable to them. ' I was given a counsellor who had absolutely no experience or idea of what I was going through. I had to find and pay for one myself in the end'
- The CA is a live document that should move with the situation and be referred to regularly.
- Stigma around asking for one – means they think I'm not coping.

### **Question 4**

- Feedback from parent carer – lack of knowledge. No one listens, so makes me feel like no one cares. Dealing with professionals is a nightmare. They should take responsibility.

- Need staff need specialist knowledge and training to deal with autism and neuro diverse people. You have to take a completely different approach with them. They must be trained to work with people who can't engage.
- Specialist service just for adults with autism
- Need the service to be pro active – don't wait for a crisis to happen – then a knee jerk reaction from services
- Act on referrals quickly
- Same recommendations for schools and early intervention – Ots/psychologists etc
- Barriers – lack of staff to supply all these services. There are so many unfilled vacancies. Not enough qualified people applying for the jobs .Then newly qualified staff are being promoted who don't have the required skills.
- LD and autism teams don't work together.

## Notes from Group 3

### Session one

- Carers packs – where to distribute, not just electronic
- Single point of contact is key
- How do we pick up people who are not identifying as carers?
- The information pack is good but dangerous without communications. If someone is alarmed by what they read or have more questions, then where do they go for help?
- Need a point of contact and someone to speak to verbally. Access is different in different situations at crisis lots of paper based online support may not be useful but outside of crisis it could work. Ideal would be a link person and a telephone number to call.
- Also, information for parents at the point of transition to adult services – in preparation before it happens, so parents know what to expect.
- Surrey Heath already have cancer navigators which work well then need to be well trained and the service needs to run smoothly so as not to cause more distress.

- Resource needs to be specialist, general help not always useful in mental health conditions. Needs to be trained to understand the condition
- Peer support is helpful but not in the absence/or as a replacement for specialised help.
- People need to know where to go to get help at point of CRISIS
- It would be useful to have crisis planning to know what to do before you get to that stage.
- The ISOLATION felt when your loved one is first unwell is overwhelming
- “You don’t know what you don’t know” and feel totally bewildered, you need someone who understands and is in a similar position as often friends and family don’t understand.
- Would be useful when person finds a service to know what is immediately available for them and plan for crisis – to include in service spec now and future planning not just immediate need.
- Carers don’t always come n same entry point to need to work with system to capture carers at all entry points e.g. Hospitals, charities, CAMHS
- Someone whose child enters CAMHS is not identified or referred to as a carer at al – need whole family approach and providers need to be asking these questions when person access services for first time – need to be trained to THINK CARER.
- A central repository of all services available should be made available like a map of services

## Session 2

- A carer on the call gave a best practice example that they had experienced (albeit some time ago) they had a care coordinator that was ‘invaluable’ to her as a carer, she provided updates when her child was in hospital check in that she was ok after crisis, regularly checked she was ok and became a TRUSTED extension of the care group for her child
- Other carer cited she had no experience of any contact from anyone at any point including crisis and feels the type of support described would be fantastic
- “Someone following up just to ask how you are – means so much”
- Workforce development – making sure people are trained to identify carers in workplace and offer employees support
- Care coordinators are in Primary Care sitting in PCNs where would the carer coordinator sit and whatever goes in the service specification should sit well with what’s happening already not duplicate or conflict

- Important to have comms in points where carers could be identified – workforce, hospitals, GPs etc and in language that's not just carer for those that don't think of themselves as a carer.

### Session 3

- Carers Assessments – what are they for? What's the point of them?
- If no one identifies you as a carer e.g. camhs service then you won't be offered and assessment
- Multiple entry points 'no front door' where you can be identified and given information
- Carers assessments can feel like tick box if nothing good comes from them
- Seems to be linked to information and advice if carer assessment is carried out by point of contact then all linked up.
- Lots of people think it's just financial support so don't follow up
- Person doing the assessment needs to be trained to understand the conditions and understand as different carers have different needs.
- Communications should be in hospitals for identifying carers and info about assessments
- Should be clear on next steps e.g. if you are eligible X will happen if not eligible then X will happen

### Session 4

- One carer said this topic was the hardest thing to deal with as a carer the inability to communicate or get information from the professionals involved in the care of her son
- Hospitals even with permission to talk to parent from child – say they need permission which stalls them, made to feel like nuisance when ringing for updates – encouraged to not contact rather than stay in touch – should let parents/carers know what to expect, best time to call, where to get information not made to feel like a pain
- Carers should be involved in the plan – they won't communicate about that but carer expected to pick up plan after discharge
- Same in community – no communication – needs to give skills to carer to help themselves, give updates and give a crisis plan – need to know where to go and when
- There needs to be someone in the system to help

- Keeping the carer informed is what is best for the patient, carer and is more efficient than the carers calling numerous time for updates with no luck.
- It should be training for those in system to understand the importance of communications with carers and relatives.
- The carer in the group said this works better in other areas and her son was sectioned out of area it was a different experience, the consultant rang and explained – never had a consultant ring in Surrey.

## Notes from Group 4

### Question 1

#### Information on services, conditions and raising awareness for those who may not see themselves as carers

- Not identified as a carer when both kids assessed for CAMHS, they never even mentioned it. Would have been really useful to have someone when we were at CAMHS actually speak to the parents and make them start to realise that they may be a carer. Until you realise this you don't realise about any benefits, carers assessments etc so the earlier the better.
- Services always seem to have boundaries and they send you to all different agencies. No one seems to co-ordinate it and there is no central point. Would be great to have a one stop shop for information and access.
- Maybe when parents go to CAMHS, there could be a designated person assigned to take charge of them as carers too
- Could go on the CAMHS checklist to make sure the parents/guardians are somehow flagged up and someone contacts them with regards to being a carer.
- Sometimes the information that we receive as carers is overwhelming. It's too much to take in when you are already going through a very stressful and difficult situation dealing with a child with mental health problems. Would be great to have something clear and simple to read. Often children with additional needs have parents with additional needs so when bombarded with diagnosis and then too much information, it's too much to process with no support.
- Need a contact who can support the carer and family unit and take a judgement on how much the family unit can cope with and then feed them information accordingly and over a period of time if necessary.

- A contact in social services to guide you through the benefits and things to support you as a carer would be ideal.
- Carers don't have lots of time on their hands to rifle around for information, they need a one stop shop or few points of contact who know them, know their situation.
- Professionals need thorough training to know what it looks like to be a carer and to therefore identify them quicker. This is particularly relevant with children. Could therefore offer early support, carers pack, carers assessments, benefits. Maybe more training at the first point of contact i.e. GP, school, CAMHS to identify potential carers and flag this up. Could flag it up and give them a number to ring?
- Would be good to plant the seed early on of - am I a carer as parent carers in particular don't always recognise it straight away.

## Question 2

### Access to and continuity of practical support for carers and their wellbeing.

- Recognise that to have one person is tricky.
- Vital to have more support in the school system. Key point of contact. School and CAMHS don't communicate. A contact in the school would be useful – they should therefore know the child and the family.
- When discharged from CAMHS felt like going off a cliff into black hole and there was absolutely nothing. Continuity for the carer is needed. Once a carer is registered as a carer, they should have a continuous point of contact and if this person leaves then they should be handed over directly to someone else. Carers need continuous support.
- School is where you pick up on a lot of these problems early on – need a designated person in the school. School and CAMHS must link up, there must be a person to bridge this gap between the two.
- You need a named person to help the carer with this mass of information and to navigate the journey. Completely overwhelming
- Used Surrey and Borders Point of crisis last night – they were excellent. Someone on the phone to speak to, someone who took time and someone who clearly gave instructions – do step 1, step 2, step 3. It was a calming and not overwhelming experience even though the person I cared for was in crisis hence the call
- Need for carer to have 24/7 point of contact. Not all carers need it but when you are in a crisis you may need it. Feels like carers assessments would be fine if the services exist that you need.
- You need to have regular appointments, a regular check in with a known contact. These can be altered in frequency as the situation alters
- To be able to speak to someone on the phone
- CPA mentioned Space2bYou service – SCC pay for it, it's 12 sessions online. V flexible. Looks at how is everybody affected. Working as a family unit.

### **Question 3**

#### **Carers assessments**

- Quality of the outcome of the assessment vital
- Systemic work is very helpful – working with the unit, the system, the family
- Never been offered one. Desperate for respite
- Only just heard of them and got referred to Action for Carers
- Negativity around what a carers assessment actually is. Didn't understand what a carers assessment was. Feels quite invasive and like being under the spotlight. Perception was that it was going to be like being judged.
- About identifying that there would be a positive outcome from it. What's the point in having an assessment ?
- Need to emphasise the benefits of the assessment – as majority of carers don't see the value
- Feel that there is a big gap between what carer actually needs and the services that are available
- Carers doubtful about the quality of the care (respite) that may be offered. How do they know it's going to be good care and right for the person they care for? How can they relax if they don't know.
- Integrated care – carer support needs to be an integrated support service and collaboration between the services. Or you commission a service that integrates across all the other services that have contact with carers.

### **Question 4**

#### **Challenges on working with professionals**

- Relationship with the professional and the patient – so as a carer to what extent am I recognised as that persons' advocate and what does that entitle me to?
- Recognition that every patient should be entitled to an advocate rather than just assuming the patient is self-advocating. And if the professional feels the patient should self-advocate, there needs to be support for the carer for this transition.
- Not viewed as a carer, viewed as a parent. So feel judged, feel the diagnosis of my child is overlooked and that they consider the behaviour to be a parenting issue
- Feel powerless, overwhelmed and exhausted as a carer. Feel the professional has all the power and therefore you don't feel able to



complain to the professional. You worry if you complain that you will not get access to that service anymore, you may lose help etc

- Needed someone outside of the structures that I could go to
- Consistency. You never know which professional it would be each visit
- Independent body outside of the situation
- Advocacy service outside that is non judgemental
- Proper trained individuals, trained in mental health. Empower professionals to be fully trained and as knowledgeable as possible before entering a family home or a new situation with a new individual
- Training is paramount !



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