

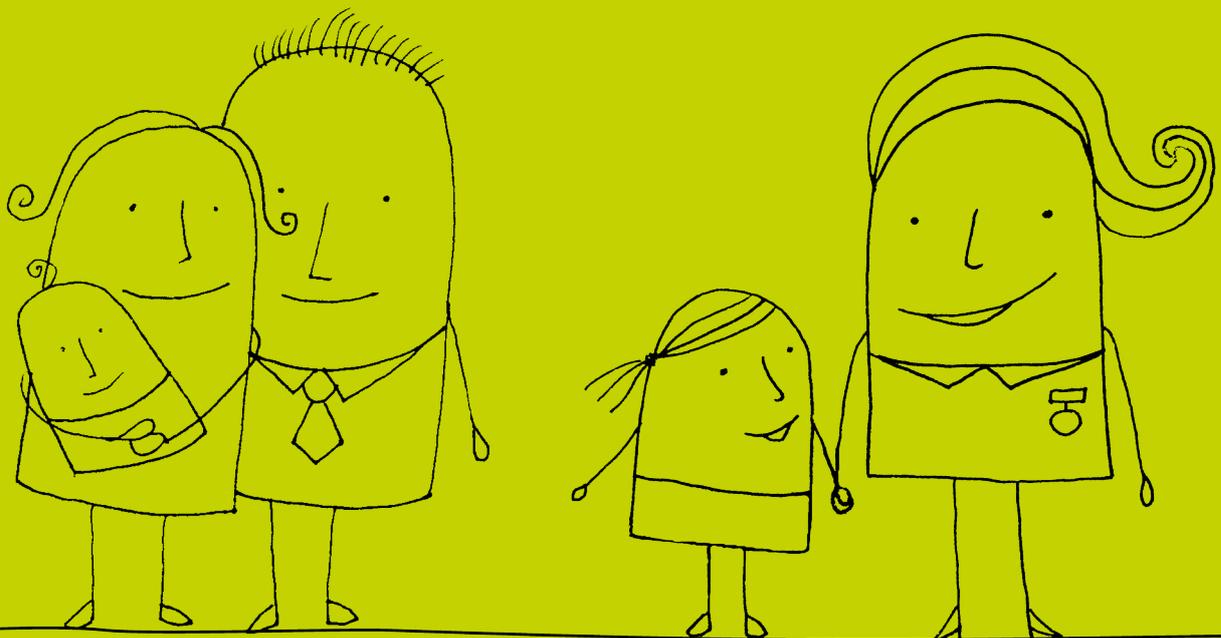
Patient and Client Council

Your voice in health and social care

Carer's support and needs assessment

**Experience of carers of people with learning disability and
mental ill health**

February 2017



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Foreword

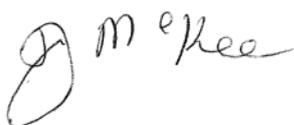
Dear Reader,

As chair of the Bamford Monitoring Group (BMG), I am delighted to be asked to contribute to this publication on behalf of the group.

At a BMG 'Planning Ahead' event held in 2016 many carers reported that they felt let down after having a carer's support and needs assessment. As a result the BMG decided evidence should be gathered to understand the extent to which assessments are providing the support needed for carers within mental health and learning disability.

The expectation is that such assessments are there to help carers and whilst the evidence collated on the whole reflects positively on staff engagement, the lack of follow-up reported on, is unacceptable. Carers save the Health and Social Care (HSC) services a vast amount of money hence, it is disappointing that this report highlights how the system as failed them. Unfortunately, limited follow-up action actually results in an additional burden to carers and a misuse of HSC resources. It was also notable that stories shared by carers focussed somewhat on better services for those they care for, rather than what support they required; which is an indictment of current service provision. I therefore conclude that based on this report, that the carer's assessment process should be improved so that it results in meaningful and ongoing support for carers.

Finally, thanks are extended to those carers who shared their personal experience with us, as without your contribution this report would not have been possible.



John McKee

(Acting) Chair of Bamford Monitoring Group

Executive Summary

Between May and August 2016, we talked to ten individuals caring for a family member with a mental health condition or learning disability about the Carer's Support and Needs Assessment (CSNA). The aim was to understand people's experiences of having an assessment, from the process of getting referred through to the outcome of the assessment. We also wanted to find out if having an assessment had made a difference to their lives and if it had helped them to continue in their role as carer.

All the carers who took part in this study gave emotional accounts of their daily lives as carers, which they described as constant, time-consuming and demanding, both physically and mentally.

Key findings

- All the carers we spoke to felt that they were not fully supported in their role as carers - practically, financially or emotionally;
- The interviewees had mixed experiences of the referral process for a CSNA. Five people were referred for their first assessment by a social worker and five people heard about the assessment from another source, such as family, friends or other carers and had to request an assessment themselves;
- All the interviewees said they received very little information about the CSNA in advance;
- The majority of carers (seven people) interviewed said that their experience of the process of having a CSNA was positive and that the person who carried out the assessment showed understanding and empathy;
- The carers we interviewed said that they did not know what to expect as an outcome to their CSNA, but respite, befriending services, extra domiciliary care and preparations for future independent living were the most frequently voiced hopes and expectations;
- Most carers (eight people) were disappointed in the outcome of their CSNA as they received little follow-up contact and little or no extra support as a result of the assessment;

- More than half the carers (six people) referred to the CSNA as a 'paper exercise' or a 'box-ticking exercise';
- The carers we spoke to recognise the value of the CSNA as a means to assess the needs of the carer and to identify what support might help to make their lives as carers easier. However, almost everyone was disappointed and frustrated that they were offered little or no support as a result of having an assessment.

1. Introduction

1.1 Northern Ireland Carer's Support and Needs Assessment

Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage without this help because of frailty, illness or disability.¹

In Northern Ireland, Carer's Support and Needs Assessments (CSNA) are a way that Health and Social Care (HSC) services provide help to carers.¹ The Carers and Direct Payments Act (Northern Ireland) 2002 imposed a statutory duty on HSC Trusts to inform carers of their rights to an assessment and to be considered for services to meet their own needs.

The CSNA looks at each carer as an individual, with their own personal circumstances, and will identify any particular needs they may have as a result. The assessment is an opportunity for the carer to help the social worker understand the impact that caring has on them and to talk about the services they may be able to receive to support them in their caring role. Aspects of the assessment include:

- The care and support the carer gives;
- The carer's own health;
- How caring affects the individual;
- The support the carer currently receives and whether they feel this is adequate;
- The carer's finances; and
- The carer's views on the future.

The assessment should, therefore, consider what would support people in their caring role. This may include:

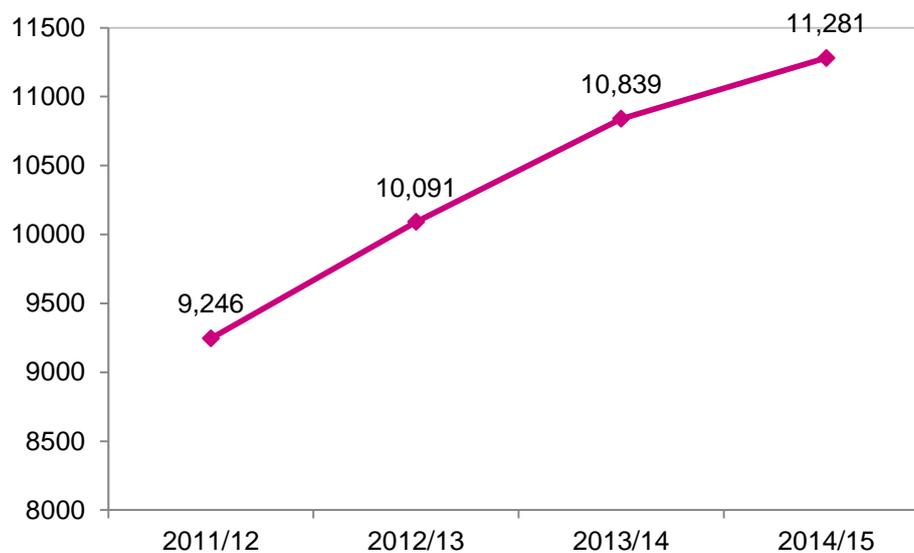
- Training;
- Contact with other carers;
- Emotional support;
- Respite; and
- Practical equipment aid.

After being assessed the Trust must consider what services (if any) can be provided to the individual as a carer. The individual should also be given a copy of their assessment. A CSNA may also be carried out to determine whether or not the support provided continues to meet the needs of the carer in sustaining their caring role. If the services are found to be inadequate a reassessment can occur.

1.1.1 Carer's Support and Needs Assessment Statistics

In recent years, there has been a year-on-year increase in the total number of assessments that have been offered to carers, peaking in 2014 at 11,281 (see Figure 1.1). Between 2011/12 (9,246) and 2014/15 (11,281), there was a 22% increase in the number of assessments that were offered to carers.

Figure 1.1: Total number of assessments offered over time (2011/12-2014/15)

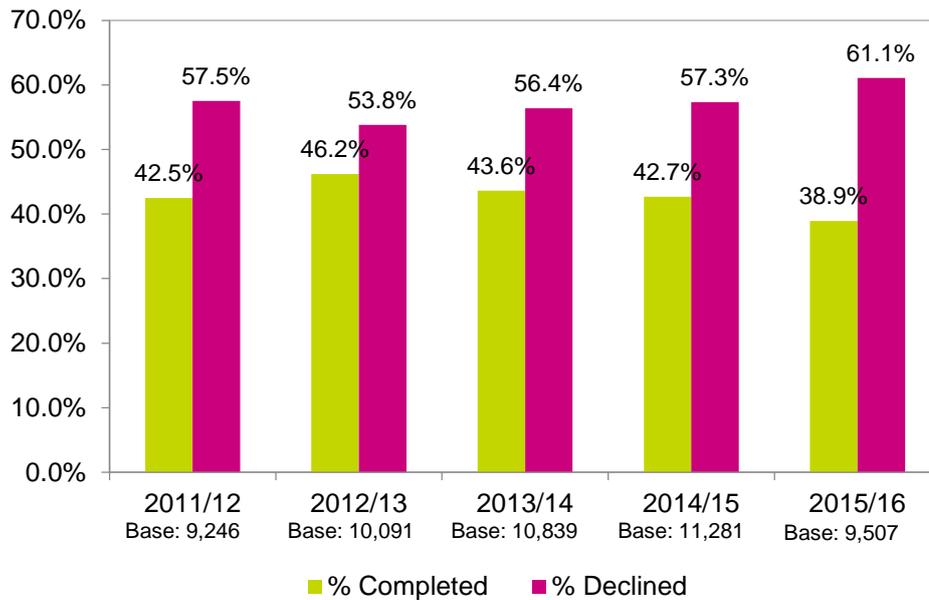


Source: DHSSPS Carer's assessments and reassessments statistics **2015/16 figures based on current available statistics (April-December)

While there has been an increase in the number of assessments offered to carers, a higher proportion of carers have consistently declined the offer of an assessment compared to those who have accepted and completed an assessment. Carers gave a number of reasons as to why they declined the offer of an assessment, which included: the carer felt that they did not need any support (28%); the carer felt that

the time/place/environment offered was unsuitable (23%); the carer did not see themselves as a carer and, therefore, did not see the assessment as relevant (17%); the carer felt that the assessment would be too complicated and time-consuming (7%); and the carer sees their caring duties as a private matter which they prefer not to discuss (7%).¹

Figure 1.2: Number of assessments completed/declined (2011/12-2015/16)

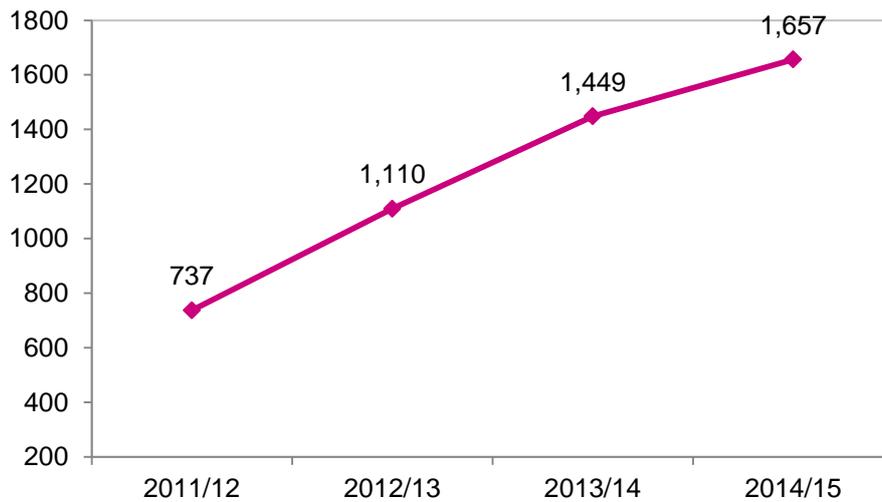


Source: *DHSSPS Carer’s assessments and reassessments statistics **2015/16 figures based on current available statistics (April-December)*

Recent statistics have also shown that a higher proportion of mental health carers have declined an assessment than have completed one (34.9% completed, 65.1% declined), whereas, in contrast, a higher proportion of learning disability carers have accepted and completed an assessment (69.6% completed, 30.4% declined).

Following the completion of an assessment, if it is deemed that the services provided are inadequate, carers will be offered a reassessment. Since 2011/12, the number of reassessments that have been offered to carers have increased year on year, peaking in 2014/15 at 1,657 (see Figure 1.3). This represents a 124% increase in comparison with 2011/12.

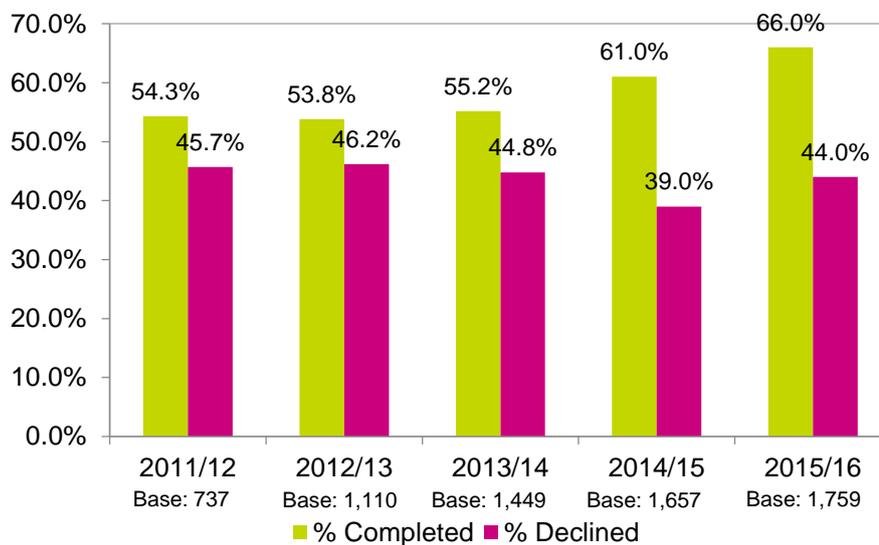
Figure 1.3: Total number of reassessments offered over time (2011/12-2014/15)



Source: DHSSPS Carer's assessments and reassessments statistics **2015/16 figures based on current available statistics (April – December)

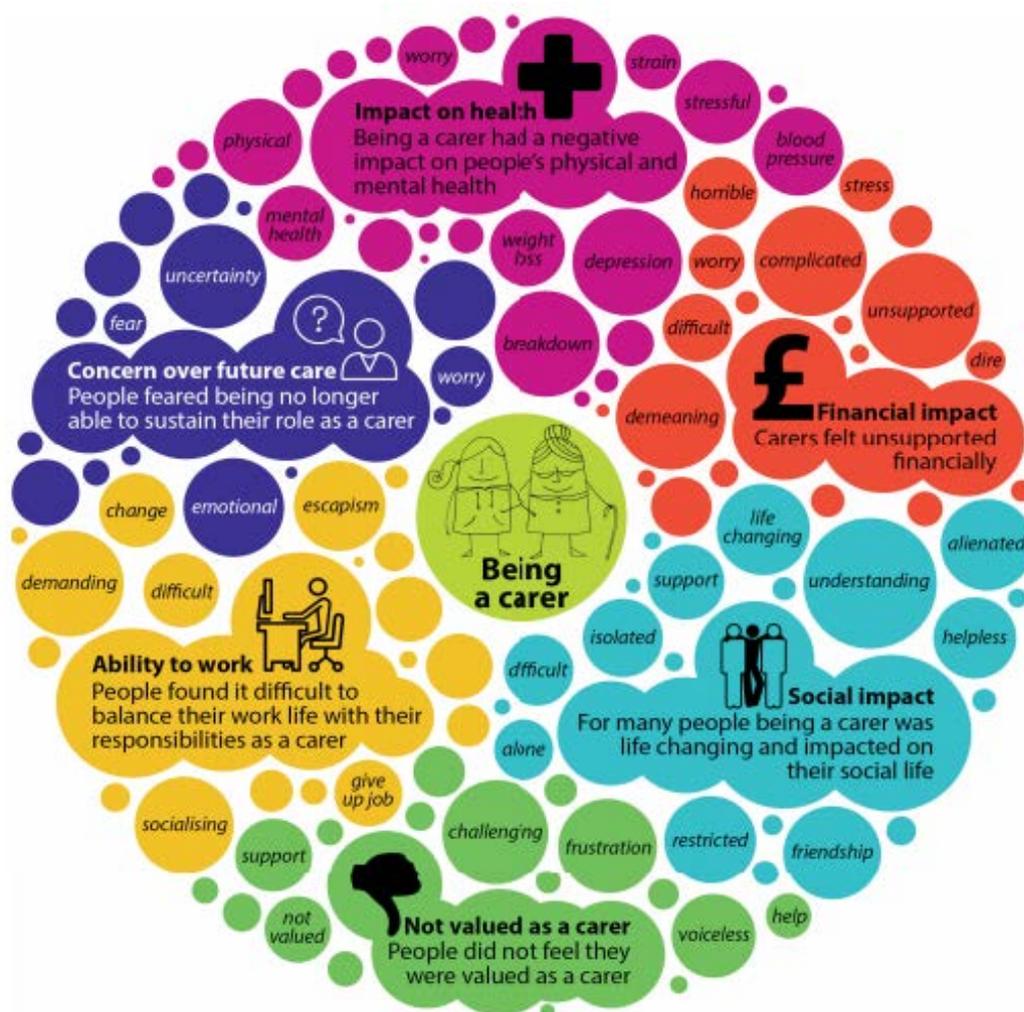
Over the past number of years there has consistently been a higher proportion of carers who have accepted and completed a reassessment in comparison to those who have declined one (see Figure 1.4).

Figure 1.4: Number of reassessments completed/declined (2011/12-2015/16)



Source: DHSSPS Carer's assessments and reassessments statistics
 **2015/16 figures based on current available statistics (April-December)

Figure 1.5: How being a carer impacts on different aspects of a carer's life



The work of the PCC has found that, while caring impacts on many aspects of people's lives, carers often do not feel recognised for the role they provide or feel supported.³⁻⁵ Through our work with the Bamford Monitoring Group (BMG), people have also told us that mental health and learning disability carers need more support than is currently available to continue in their caring role. Specifically, at the BMG event 'Planning Ahead' (2016) a common theme among carers was the lack of any outcome or action following their CSNA.

Carers often work tirelessly and selflessly to support the person they care for, but receive little or no assistance, respite or care themselves. It is clearly evident from the PCC's engagement with carers that this support is greatly needed.

1.2 Aims and Objectives

The aim of this project was to engage with mental health and learning disability carers to understand their experiences of the CSNA and to identify whether having an assessment has made a difference to their lives.

The key objectives of this project were:

- To engage with carers who have had an assessment to give people an opportunity to express their views on the process;
- To identify the main outcomes carers want from an assessment;
- To understand people's experience of having an assessment; and
- To establish the key issues people experienced with the assessment process.

2. What we did

2.1 Participation in the project

To recruit participants to this project, a public call-out was included in the PCC Membership Scheme newsletter. We also promoted the project by sending flyers to carer's groups and carer's coordinators across Trust areas.

In targeting the sample we sought to ensure representation of both mental health and learning disability carers who had recently had an assessment (defined as having an assessment in the last 12 months) across HSC Trust areas. Ensuring representation of gender and age proved difficult, with only one male carer participating in the project.

Between May and August 2016, we talked to ten mental health and learning disability carers about having a CSNA – see **Table 2.1**. This included three people with a diagnosis of mental ill health and a learning disability.

Table 2.1 Interviews with carers

Interview	Interviewee	Carer for...
1	Male and female carers, ages not given	Son, 38 years, learning disability and mental ill health
2	Female, over 65 years	Son, 32 years, learning disability
3	Female, 55-64 years	Brother, 50 years, learning disability (also caring for partner, over 65 years with brain injury)
4	Female, 35-44 years	Two children, seven and four years, learning disability
5	Female, over 65 years	Son, 21 years, learning disability
6	Female, age not given	Son, 19 years, learning disability and mental ill health
7	Female, 35-44 years	Two sons, 20 and 23 years, learning disability. Currently also caring for husband

8	Female, age not given	Daughter, 20 years, learning disability and mental ill health
9	Female, 25-34 years	Mother, age not given, mental ill health
10	Female, 35-44 years	Son, eight years, learning disability

2.2 Information collection and analysis

A topic guide was developed to gain an understanding of participants' experience of the CSNA. The topic guide was designed around a typical assessment journey to aid participants' ability to recall their experience of having an assessment. Key areas of the topic guide included:

- Establishing the impact of being a carer;
- The process of getting an assessment;
- Experience of having an assessment; and
- Outcome of the assessment.

One-to-one in-depth interviews were used for this project to allow for the collection of detailed information about participants feelings, perceptions and opinions of the assessment process, which was different for each individual. Interviews were recorded and transcribed verbatim and a thematic analysis of transcripts was undertaken to examine responses to identify prominent, recurring themes.

3. What people told us

This findings section reflects what the people we interviewed told us about their experiences of having a CSNA. It looks at their experiences in four main areas:

- Life as a carer;
- The process of getting a CNSA;
- Experience of completing a CNSA; and
- Outcome of the CNSA.

3.1 Life as a carer

Key quotes...

“I am just a carer now and that is it. I am not me any more... I have sort of stopped”

Interview 3

“[Caring] affects every part of my life... My whole life just basically came to a standstill and I now have to work my life around [children]”

Interview 7

“There have been times when I sort of think, gosh, is this all I have to live for?”

Interview 2

“I think it’s a time thing, it’s every moment of every day. You’re constantly thinking of the other person”

Interview 8

All the carers we interviewed took time to describe the impact of their caring role on their daily lives. Caring was described as a full-time job, one that was time-consuming and demanding, both physically and mentally. The word ‘constant’ was often repeated as carers spoke about how the person they cared for was always their first priority and the main thing they thought about throughout each day. It was clear from the interviews that caring greatly affects most people’s personal freedom and makes having a social or working life outside the family home very

difficult. Many of the carers (at least four people) we interviewed had to give up their job or reduce their hours due to the pressures of their caring commitments.

It is evident that caring full-time for someone at home has a huge impact on the entire household. The carers we interviewed who had other children or close family living at home spoke emotionally about the affect their caring responsibilities had on their relationships, especially the limited amount of time they could dedicate to other members of the family.

All the carers we spoke to felt that they were not fully supported in their role as carers. In fact, most of the interviewees (nine people) clearly felt a distinct lack of financial, practical and emotional support. Some even said they felt completely alone and isolated. It is important to note that carers did add that many of the staff they had come into contact with were understanding and supportive, but that the services and resources to provide any meaningful support were simply not available.

While some carers (three people) did acknowledge that being a full-time carer could be rewarding at times, people generally felt that the high demands of caring far outweighed any rewards. The fact that most of the interviewees felt unsupported and isolated made it more difficult for them to identify positive aspects of being a carer.

Carers were asked during their interview if they felt that their expertise as a carer was valued. Some people found this question difficult to answer. The general impression from the interviews was that people in health and social care often talk about how much they value carers, yet the carers themselves feel this appreciation is not realised in terms of practical support.

In one interview, a carer made the point that unpaid, family carers were saving HSC services a huge amount in terms of money and resources, and that those carers should be valued and appreciated for the contribution they make to society. They suggested that a good step in providing carers with a voice would be to employ a full-time carer's advocate in every HSC Trust.

3.2 The process of getting a Carer's Support and Needs Assessment

Key quotes...

"We kind of just fell into it. It wasn't that somebody somewhere said: 'These people are carers, they have been caring for a long time, they have a lot of stress in their lives, maybe we should get them a Carer's Assessment.'... It was more by chance"

Interview 1

"It was never made very clear, you know, that I have this right to needs... It was never, ever made clear... there was never any information given about what we would be entitled to"

"I was just hoping that they would be a bit more aware of my needs and that I would get some sort of help"

"I suppose more support for my daughter when she was at her worst... I think I thought I'd finally be able to get some help. I suppose that was my main priority. Hoping that I'd get some help to cope"

The carers we interviewed first heard about the CSNA from a number of different sources. Five people said that the social worker for the person they cared for told them about it or referred them for their first CSNA.

However, five people said that they heard about the CSNA from a source other than HSC services, such as family members, friends, other parents, or at an event for carers. They subsequently requested an assessment themselves from the social worker. A few carers (two people) noted that their GP never mentioned the availability of a CSNA to them, despite having knowledge of their home situation and the demands that caring had taken on their own health.

All the carers we interviewed said they were given very little information before they received their assessment and that the purpose of the assessment as an opportunity to assess their needs as carers was not really made clear in advance. As a result, carers did not know what support they were entitled to or what to expect as an outcome to their assessment. Some carers (three people) suggested that, if they had been better informed in advance of the assessment, they would have felt more confident and better equipped to answer the questions about their caring situation and needs when the assessment took place.

When the carers we interviewed did talk about the support they needed and hoped for as a result of having a CSNA, it was usually something that would be of benefit to the person they cared for rather than something specifically for themselves. Respite or a befriending service was the type of support most frequently hoped for among the interviewees. A couple of the carers (two people) hoped for some practical support, such as extra domiciliary care.

For two of our interviewees, an important aspect of having a CSNA was to identify how their needs as carers were changing as they got older. This was especially true for those caring for adult children, who felt they needed support to make preparations for the future when they would no longer be able to care for their child.

One interviewee, a full-time carer for a parent, felt that, in hindsight, the CSNA could have been an opportunity to start to discuss and put in place preparations for their parent's future care. This is something they would consider for a future reassessment.

3.3 Experience of completing a Carer's Support and Needs Assessment

Key quotes...

"You think: here is a professional who I have now opened up to, they know and they are going to help us. You are passing it on so you don't feel as isolated and alone... So there is something in it, it is not just airy fairy nothingness. It will have a value and there will be some kind of an outcome from it. Now we weren't expecting miracles, just something, you know?" Interview 1

"You give an answer and they tick the box 'yes' or 'no' but, to me, there is so much more... I just feel that they're robot-style, they are not really taking on board that there is a person, you know. If you say the right word, they tick the box, but it is not developed. I don't think it is very good" Interview 2

"I think it was all very positive... I actually thought it was very good. For the first time in a long time somebody had asked me my feelings and my thoughts and views, and what I kind of go through in my caring role" Interview 9

"I think the reasons behind having the assessment are good but, if nothing is going to come out of it or nothing is going to happen, nothing is ever going to be learnt from this, what's the point?" Interview 6

All the carers described very individual experiences of undergoing a CSNA. All the interviewees had the assessment carried out by a social worker or key worker for the person they cared for and most of the assessments took place in the carer's own home (only one carer went to a HSC centre for their assessment). For the most part, people were happy with this because they felt more relaxed at home and the person carrying out the assessment could see them in their own environment.

However, two carers noted that, in hindsight, they would have preferred to have the assessment in another venue. One carer felt that a neutral venue would keep things

more professional and maybe lead to a better outcome, while the other carer felt that she was too distracted carrying out caring duties during the assessment to give her full attention to what the social worker was saying.

The majority of carers (seven people) we interviewed said their experience of actually having a CSNA was largely positive. They felt that the person who carried out their assessment was competent, sensitive, listened to what they said, and showed empathy and understanding. The most positive aspect of the entire assessment process for some carers was that, for the first time, a professional was actually taking the time to sit and talk to them about their experiences of being a carer. They appreciated the opportunity to tell their story.

However, three people felt as though the social worker was not really interested in hearing about their needs, but was there to simply get the form filled out. More than half of the carers (six people) referred to their experience of having a CSNA as a “paper exercise” or a “box-ticking exercise”. These two phrases were often repeated during the interviews.

3.4 Outcome of the Carer's Support and Needs Assessment

Key Quotes...

"The whole process is tedious... you hear about it [CSNA], you eventually get to do it, you're not quite sure what to expect, but what I found is that none of it has been addressed and you have to keep on. It is tedious. You have to keep going back to them to remind them and, you know, try to get things put in place" Interview 2

"I don't know when you actually do them what is done with them, to be perfectly honest. Really, I don't know what they are for. Once you do them, fill in all the bits and pieces... that seems to be it done and dusted, in a folder and forgotten about" Interview 3

"I've rang and rang and left messages, but no one gets back to me. Especially after me taking a big step in calling them to come out and for them to dissect your life and then not to hear anything is not acceptable" Interview 4

"It's [CSNA] not worth it. It's okay them filling in the form, but if they aren't going to follow up what is in the form, there is no point" Interview 8

Most of the carers (eight people) we interviewed said they had little or no contact or follow-up from the social worker after their CSNA. A couple of the carers (two people) said they found this lack of communication to be the most frustrating aspect of the entire assessment process. The only people who received a copy of their CSNA were those who phoned up and repeatedly requested one.

For most carers (eight people), the outcome of their CSNA was overwhelmingly negative. Almost everyone said that the support identified during their assessment had never materialised. More than half the carers (six people) we spoke to felt now that the assessment was a 'waste of time' or a 'pointless exercise'. No one received a new care plan as a result of having the assessment.

For those carers who actually had a positive experience of having the CSNA carried out, and who had needs identified during the course of that assessment, the lack of any real outcome was a huge let-down. It was evident from some of the interviews that hopes and expectations had been built up as a result of a positive assessment, only for carers to be left very disappointed.

It is worth noting here that some carers also described the assessment as an emotional and upsetting experience because they had to talk about some very difficult and personal aspects of their lives. For there to be little or no positive outcome at the end of a process that could be at times challenging, emotional and draining was described as “not acceptable” and even “cruel”.

One carer went as far as to say they felt “stupid”, misled and embarrassed for firstly expecting support as a result of having a CSNA and, secondly, for recommending the assessment to other carers at a support group they attend.

Only two carers said they received the support identified as a result of their CSNA. One carer received Direct Payments to help employ carers for her son. However, although the carer said the Direct Payments did make a positive difference to their lives, they would much prefer respite. They felt that Direct Payments were not really an appropriate means of providing support for their son as he has behavioural issues, which makes it difficult for them to find suitable carers. They also found it stressful and time-consuming to organise schedules and pay so, ultimately, Direct Payments do not provide a lot of relief for them either.

This carer had also looked into treatments, such as massage, which were offered as part of the CSNA, but there were never any spaces available. Other carers also noted that they were offered away days and services such as treatments, courses and social events as a result of their assessment, but no matter how promptly they contacted the provider to book a place there was never any availability.

The other carer who received an outcome to their CSNA was awarded a one-off carer’s grant. However, even this carer felt that the assessment was something of a missed opportunity, largely because they received so little information about the

assessment in advance and did not know what they were entitled to ask for in terms of more long-term support.

4. What could be improved?

The carers we interviewed made a number of practical suggestions as to how the CSNA could be improved to make it a more positive and useful experience for those involved. For example, as noted in the previous section, a common suggestion in the interviews was that carers could receive more information in advance, particularly on the purpose behind the assessment and the support options available to carers as an outcome of the assessment.

A few carers felt that the CSNA document was too rigid and inflexible. They suggested that the assessment should be more adaptable to, and reflective of, the individual needs of different carers and the person they care for.

Two carers proposed that the CSNA should take into account that a carer could be caring for two or more people. They highlighted some of the issues involved in caring for more than one person. One carer took an even wider view by suggesting that the CSNA should not simply focus on one individual, but look at the entire household when determining the level of support that was needed.

One carer suggested that a more effective CSNA process would consist of three distinct parts: a first meeting for an informal chat to hear the carer's story and understand something about their life, a second meeting to talk specifically about practical needs and support required and a third meeting to communicate to the carer what support they are able provide or, just as importantly, are unable to provide at that time.

5. Conclusion

It is evident from these ten interviews that mental health and learning disability carers lead daily lives that can be demanding, both physically and emotionally. The carers who took part in this project spoke very openly about the challenges and demands of their caring role. It is also clear that every carer we spoke to would benefit greatly from more practical and emotional support.

The interviewees had mixed experiences of the referral process for a CSNA. Half the carers found out about the assessment from a source other than HSC staff and had to request an assessment themselves. However, the majority of people said their experience of actually having the CSNA carried out was quite positive and that the person who carried out the assessment showed understanding and empathy.

Almost all the carers we interviewed received little or no information in advance of their assessment and, as a result, many said they did not know what to expect as an outcome. Where carers did identify the type of support they would like to be offered, in most instances it was actually something of benefit to the person they cared for, such as a befriending service, a suitable respite place or preparations for future independent living, rather than something specifically for the carer.

Most of the carers were disappointed in the outcome of their CSNA. While many people recognised the value of the CSNA as a means to assess their needs and identify what support might be of benefit to them, almost everyone felt let down and frustrated that they were offered little or none of the support identified as part of their assessment.

6. Recommendations

A number of recommendations can be made from the findings of this report:

- People should be given clear information (either written or electronically) detailing:
 - The purpose of the CSNA so that they have a better understanding of the assessment as an opportunity to establish their needs as carers.
 - The assessment process itself so that carers know what to expect and can prepare in advance of the assessment;
- Carers should receive a copy of their assessment with regular, informative follow-up to discuss: how their assessment is progressing, what needs have been identified as a result of their assessment and what, if any, support they can expect to receive with agreed timescales;
- The CSNA is a legislative requirement and yet the evidence from this small sample suggests that it is not proving effective for many carers. Further work is required to understand the experience of all carers and to review the measures used to monitor consistency of services available and the outcomes of assessments.

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