

A STUDY INTO THE EXPERIENCES OF SERVICE USERS, PARENTS AND CARERS OF THE CARE ASSESSMENT PROCESS.

Healthwatch Walsall is the independent consumer champion for health and social care in your local area. Our role is to gather the views of people's experiences of local health and social care services. As part of our role, we carry out evaluations of services to understand the experiences of people who are using them. We share the feedback we collect with the service providers and commissioners and work with them to look for ways in which services can be improved.

Each year Healthwatch Walsall establishes work priorities based on public engagement, and intelligence gathering.

One of these priorities has been looking at local people's views on care assessment processes. We wanted to collect feedback from adults and parents of children who have experienced care assessments by undertaking short interviews, in order to gather information and case studies. Our informal interviews were undertaken with service users and relatives to give us a snapshot of some views. Whilst Healthwatch Walsall understands that there are a number of factors influencing personal care packages, rationale for changes and that there have been financial cuts to providers budgets thus it is important that local people highlight how in their experiences they feel they have been affected by change.

This project came about due to people telling Healthwatch Walsall that they have been impacted by the care that they receive as a result of changes to their care assessments. We wanted to find out whether there was commonality to this issue.

Methodology

We used a survey with a series of questions and prompts to gather people's views. The questions were developed, based on the experiences of someone who had been through the care assessment process several times with their son.

Questions were asked around access and support from Social Workers, assessments access and changes, care and support plans, personal budgets, Personal Assistants (PA's).

Quality Plan

Healthwatch Walsall has a responsibility to ensure that the research it undertakes and creates is of high quality and aligned to best practice across the industry. Research ultimately provides the

evidence on which sound decisions should be made, which is why it is important to state up front how quality was ensured during this project.

During the project ECS adhered to a strict data protection policy that ensured that everyone handling and managing personal information internally understood they were responsible for good data protection practices. If there were any queries received about handling of personal information they would have been promptly and courteously dealt with.

The methods of handling personal information are regularly assessed and evaluated. Necessary steps were taken to ensure that personal data was always kept secure against unlawful loss or disclosure.

The service users that we interviewed had a varying degree of support needs and their concerns varied from issues relating to funding through to care assessment and the support being received. Below we have broken down the main generic issues that some adults and children's family members have faced around the assessment process:

Our Findings - Adults Experiences

Consistency of Care

Consistency in care quality and also the consistency of those providing care has been highlighted as a fundamental part of the care process. Changes in care staff that attend to provide care can have a real impact on the service user particularly if they are vulnerable.

Some service users informed us that there was a lack of consistency in the care being received. One service user informed us that some staff were qualified to take bloods and to undertake other more complex care, but some day staff would arrive who were not qualified to undertake certain tasks. We were also informed that some service users who had dementia found it very uncomfortable and even distressing to have varying care staff visit their homes with little consistency. "The agency often changes the staff who were meant to visit me on a regular basis."

Care Assessments

Care assessments and care plans have been highlighted as the most prominent issues through our engagement with service users. We have been informed that some assessments have not been fully carried out to support service user needs, or that there has been varying degrees of understanding of needs depending on the Social Worker that has carried out the assessment. We were informed by two service users that Social Workers did not fully understand the support needs of their client.

Ms D receives the same number of hours of support now and that the full assessment was undertaken 8 months ago. She receives 8 hr night care support Monday to Friday but not at the weekends and stated, "I'm not cured at weekends". Social Worker has ignored my support needs completely and taken away relative carer weekends.

Ms D also informed us that the Social Worker had refused to fight for more respite care for her needs. A number of people have highlighted frustrations in the care assessment process with the main issues being:

- The length of time it takes to arrange to undertake a full care assessment.
- Varying views from the client/family member and the Social Worker in relation to what is needed.
- Support packages being lowered with no full explanation/rationale.
- The quality of the care plans depends on the Social Worker time and impetus.
- Valuable respite care being cut for family members.
- Some people did not know that they could be entitled to care act advocacy support.

Communication

Communication between service users and Social Workers is key and the messages that are portrayed to those receiving care are significantly important. Healthwatch Walsall have been informed by some service users and relatives that they have received mixed messages in relation to what care package changes are to take place.

A service user with complex needs explained that after several care assessments it took 3 years for an increase in her benefits for her care. The service user in this case believes that the care hours have been reduced and that the Social Worker had made a poor care plan. The service user had also requested a change in Social Worker which was declined.

Healthwatch were also informed in three cases that the Social Worker was changing but it had taken a long time for a new Social Worker to be allocated and in two cases once the Social Worker had been allocated there was a lack of understanding of the service users support needs.

S doesn't have a Social Worker at the moment as she is moving. S has had 3 Social Workers over the last year and there has not been any consistency. Disability Related Expenses (DRE) funding was not included in the financial assessment

D had informed us that her support package has been lowered in the last 12 months and that the money she received was much less than normal. She has had 4 care support plans since last November 2018, but none were signed off, but she now has a new one.

As part of one of our interviews we were told by a relative whose mother has dementia that the family were becoming significantly concerned about her dementia, and at home she was becoming vulnerable and at risk. The family had wanted mum to be moved into suitable residential care and yet there were issues with getting mental health assessments/CHC assessments and changes in Social Workers had meant that updated care plans had not be undertaken. The family are now happy that their Mum is now in a residential home, but this highlights some of the difficulties service users and families face in ensuring adequate support and care plans are put in place.

Personal Assistants

Some people informed us that using PA's has been a lifeline. However, we have received some comments about difficulties with the PA recruitment process and that it is difficult for some to recruit a PA that will gel with the service user as there needs to a good relationship between the two parties.

Complex Issues

It is evident that some service users have both complex health/social care needs and with several people planning and undertaking different elements of care it can be difficult for the service user. The lack of consistency with the actual care provider can be a concern as highlighted below:

In asking does mum get the support she asked for she said no as the carer providing care in the morning has left and the agency cannot provide another carer due to the complex care required. Mum has been told to look for a carer and employ her directly, but she is finding this very difficult. She has not had a carer in the mornings since July 2018 (to date) and it is getting very difficult to cope. Mum does have a support plan, but it is not detailed enough, and she has not yet had a financial assessment. Mum has DRE expenditure and personal budget through direct payments which keeps changing and it is difficult to keep a track from one month to another.

Direct Payments

Many of the people that we had spoken to receive funding through Direct Payments and in many cases, this works well, and the funding is consistent and accurate. There have been system changes and due to care assessments, some service users have told us that their direct payment has been reduced or fluctuates with little explanation when the amount of funding received goes up and down.

This means that for some service users and families it has made planning care much more difficult.

We have been told that for some people they have reduced the PA/carer support that they receive as they cannot afford this and yet their care needs have not changed.

Our Findings - Parents of Children Accessing Care Assessments

Communication

For both adults and parents, the importance of clear and timely communication around the planning and implementation of care plans through assessments is crucial. Many of the issues around the communication and interpretation of what will be provided in care plans are similar for both children and adults.

Some of the communication issues that we were informed about include:

Two parents told us that they had been informed by the Social Worker that their child's care package would be reduce by half once they become 18 and yet their needs have not changed.

Changing Care Needs

Through this process we were able to talk to several parents with children with complex needs. In some cases, Healthwatch were informed that as the needs of children changed through time their changing care assessments have not kept pace. As an example, some parents have explained that their children's behaviour has become more demanding over time and yet the additional respite had been declined and, in some cases, reduced.

However, we were also informed that some Social Workers and nurses have gone the extra mile to ensure that care plans and the support required is updated regularly to support the care needs.

Transition to Adulthood

The transition to adult process for children with physical, learning or mental health difficulties should ensure that any aspects of care that is changed must include a gradual and agreed process of care change through transition. For some parents this has not necessarily been the case as some parents have had difficulty with financial assessment and have been informed that soon their children will no longer be able to access services due to their age. There have been several frustrations around understanding that for some young adults with complex needs it is not as straight forward as putting them through an adult care assessment as such assessments are not always designed around their needs.

Agency Support

Healthwatch Walsall were informed through this engagement that for a few children finding agencies that could provide specialist care has been difficult. One parent had informed us that a carer from the agency had left and the agency had informed the parent that they would no longer be able to provide the care package and that another provider would be required. For some parents whose child(ren) require daily care, finding an appropriate provider is not always a rapid process.

Conclusions

From the experiences of service users, parents and relatives that we have spoken to, some have told us about difficulties in accessing support from Social Workers, communication around the levels of support that people can access particularly around care assessments, support plans and support with managing Direct Payments.

Whilst undertaking this project we were informed of some general themes/views from clients and carers that we had talked to.

Common problems (views that we had obtained) include:

- Some assessments do not accurately reflect the needs of the person.
- Some care and support plans do not meet all eligible needs.
- Some personal budgets are not enough to cover the costs of the support needed, or that personal budgets are cut.
- Staff changes means that in some cases has not been the continuation of assessment processes.
- Every local authority has its own eligibility criteria for the level of support to be provided, but they still must comply with government guidelines.

It is however important to note that clients and carers have the opportunity through processes to appeal against any decision regarding their care package change post review.

Recommendations

Whilst every client/service users' needs will vary depending on their health and social care requirements there are some key areas / opportunities that could be considered:

- Service users highlighted the need for improved and consistent communication particular with Social Workers/ hose undertaking care assessments.
- Due to staff changes it is important that service user history/current needs are validated and changes to care plans made.
- It is important that service user care providers, where possible, ensure consistency of service delivery to reduce stress of change and build up a closer relationship between care provider and service user.
- All service users and relatives are made aware of the appeals process, how to access, and clear explanation of decisions given.
- Transition to adulthood. Whilst age may change, needs may not and consideration should be given to assessments being based on person centred needs not age.

Below is the template used to gather service users, carers and relatives' views.

Survey Template



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One of our current projects is looking into people's views on changes in their care packages, as a result of recent care assessments. We want to collect feedback from people who have experienced these changes by undertaking short interviews, in order to gather information and case studies. Our informal interviews will last for approximately 30 minutes.

This project has come about as people have told us that they have been impacted by the care that they receive, as a result of changes to their care assessments. We want to find out whether this is a common issue.

Your information will be kept confidential and any feedback that you give us will be kept anonymous within our report. We will not share your individual details with anyone else. Any information that we hold about you will be destroyed three months after we publish the report on our website. You will be able to view the report prior to publication.

If you need any further information about this project please contact Mr Paul Higgitt, Healthwatch Walsall Manager on 0800 470 1660.

I agree/give consent to take part in the project and understand the above.	
Name:	
Signature:	
Date:	

Date of Interview	
Name of Interviewer	
Name of Interviewee	
Name of person receiving care	
package/assessment	
Contact number	
Email address	
Social care	
Children/Adult/Transition	
Background	
Social Workers:	
Do you have an allocated	
social worker?	
How often do you see a	
social worker?	
What does your social	
worker do?	
Assessment:	
Do you have regular	
assessments?	

When did you last have an assessment?		
Was your support changed at your last assessment and how?		
Was a full assessment done?		
Do you have a care/support plan?		
Did the assessment identify all the support you need (even if you don't receive it)?		
Are you getting the support you were assessed for?		
Financial Assessment:		
Have you had a financial assessment for contributions to your care?		
Are you receiving disability related expenditure?		
Are you receiving a personal budget?		
Do you have direct payments?		
Personal Assistant (PA):		
Do you employ PA's?		

Do you have any problems employing PA's?	
Is it easy to get help about Employment?	
Do you use agency PA's?	
Are they reliable and good?	
Overall, do you get the support you need?	
Anything else?	