



were comfortable with. The service has introduced pre and post Care Programme Approach Meeting visits to carers to promote engagement between families, local services and placements. This development has helped to signpost carers to get help, assistance and increased contact with the service user and care providers. Not everyone though has engaged, and this is often through choice, e.g. anti-services, relationship breakdown. To ensure this group are not forgotten the service has developed a strategy to involve carers at their own pace at an appropriate level. The role of the OOA MHLD placement coordinator has been to develop this and to ensure quality of OOA service provision and to provide reassurance about placements particularly given the recent abuse cases in the national media.

## Plan

To address the issue of carer involvement, it was proposed that information would be gathered from a series of consultation events. This idea was presented at the Behavioural and Developmental Psychiatry Clinical Academic Group's Service User and Carer Involvement Meeting to get advice on the best ways to engage carers and to hear what they saw as the current barriers to their involvement within the service rather than rely on clinicians' assumptions of the barriers. The group offered the following advice in how to proceed:

1. To offer reflection time within the events to capture carers' issues.
2. To structure the day effectively to create an enabling environment.
3. A "do you know?" section on the services/support currently available for carers.
4. To look at different aspects of people's experiences, e.g.:
  - the financial implications of caring responsibilities;
  - exploring carers' knowledge of care pathways/systems in care;
  - carers' needs, expectations of their role and access to emotional support; and
  - support currently received, e.g. record the number of carers' assessments carried out.

## Implementation

The project proposed to engage with carers in different settings which included:

- existing carer groups, which were canvassed;
- an active presence at local events in Carers Week; and
- a series of local one day events, supported by a Charitable Funds grant.

Although this paper concentrates on the local events, findings from other groups attended have been acknowledged where used.

Two carer forums were organised and hosted locally by the OOA service. The forums were four hours long with regular breaks for refreshment. These events were advertised locally by invitation from MHLD teams, community social care teams and charitable organisations of the four boroughs of the trust both directly and via the community team. They were co facilitated by the placement coordinator and an experienced campaigning carer.

The events were open to all carers caring for someone with or who had an interest in intellectual disability. To ensure representation from the OOA group those who were unable to attend had the opportunity to air their opinions. This was initially intended to be via a questionnaire however feedback from carers during the process clearly stated that time taken to complete such questionnaires was not a valuable use of their time for two reasons: first as they had given all these opinions before and second they had not received feedback or strategies as to how their opinions were taken forward to improve the services carers receive. To this end the project adopted an agreed way forward of noting the initial findings and sending these out to carers enabling them to have the opportunity to make additional comments.

The objectives of the events were:

1. to increase carers' involvement;
2. to understand the barriers that carers face to involvement;
3. to have an increased understanding of the carer's journey through health, social services and independent sector pathways;
4. to explore the need for an OOA and/or local carers support group;
5. to inform a local carers strategy for MHL;D;
6. to ensure carers are aware of how to access health and social care organisations and understand feedback and complaints procedures; and
7. to develop carer specific information leaflets.

The agenda for both days was kept simple and both days were divided into two parts:

#### *Part 1*

- Issues faced by carers.
- Roles of carers.
- Experiences of carers.

#### *Part 2*

- Solutions.
- A wish list.

### **Event feedback**

#### *Part 1*

*Issues faced by carers.* Issues expressed by carers at the events covered both local concerns and also the system that underpins policy and national policy. Many carers feel that the system works against them. An increasing number of carers are older adults and support more than one person. The support given by carers can involve sleepovers, keeping and accompanying people to appointments, physical care and acting as a liaison between services. The latter point is particularly important when communication has broken down between services and the service user.

Carers often have 24-hour involvement with the loved one they are caring for. The toll this takes on the carer is often neither recognised nor appreciated. The current carer's allowance (Department of Works and Pensions (DWP, 2012)) is £58.45 per week. This is reduced by the amount of certain other benefits, including state pension that the carer might be entitled to. In order to be eligible to claim carer's allowance a carer must care for 35 or more hours per week for one particular individual. A carer caring for two or more people may spend more than 35 h on combined care but will not be eligible for carer's allowance unless 35 or more hours are spent caring for one specific individual. A carer on incapacity benefit is not permitted to claim carer's allowance. A carer in full-time education of more than 21 h per week of supervised study is not entitled to carer's allowance. This latter point particularly has an impact on younger carers.

The number of hours a carer spends caring, be it for one or more individual, can seriously impact on their ability to hold down employment. This then has a serious financial impact. If a carer is able to work and earns more than £100 per week (after certain deductions) then they are not entitled to carer's allowance. In term of assessment of needs many carers did not know that they were entitled to have regular carer assessments.

*Roles of carers.* From the feedback it was clear that the role of carer is multifaceted. It is a dynamic role that has to adapt and evolve to any given situation experienced by the person being supported. This means that the day-to-day task of a carer's role is ever changing.

Many carers felt that it was assumed and expected that they would readily adapt to changing circumstances with neither support nor understanding from services as to how it will effect and impact upon them and their families. Carers also felt that there were in a pressurised position with other family members who could at times be critical of decisions made and of how the carer handled varying situations.

It was clear from the events that carers are a valuable resource and have expert knowledge regarding the needs of the person for whom they are caring. However, all too often this resource is not used or used inappropriately by services. There is a need for the clinical teams to embrace the contribution of carers and not only involve them but to appreciate what they bring as an important source of information relating to the service user. This with good communication with carers will improve care for the service user.

*Experiences of carers.* The challenge and role of being a carer is often underestimated by teams. Carers often felt this was reflected in the attitudes and responses of services which served to act as a barrier to engagement. Carers at the events described feeling not only neglected but also as though they were intruding. It was reported by carers that it is often difficult to have access to a member of the medical team for queries. Patient confidentiality and the Data Protection Act were often given as reasons for non-engagement with carers (Royal College of Psychiatrists, 2012). Carers commented that often when they did get an update from staff that it could be so general it offered little reassurance such, e.g. "They are fine." This was particularly difficult for carers of service users recently placed into in-patient care. Carers reported increased feelings of helplessness as they went from responsible for caring for someone 24 h a day to in-patient care and receiving very little information.

As touched on earlier carers are generally well aware of patient confidentiality issues. They felt that their requests for information as to how things were going with the service user were often misinterpreted as wanting to know more specific details which would, of course, be confidential. It was felt that this was a barrier to good communication between the team and the carer (Staff training and awareness of all aspects of patient confidentiality could help to address this problem).

Carers also expressed their frustration with experiences of services neither returning nor answering phone calls. The participants provided a clear message that they want to be involved and contribute and not treated as if they have no responsibility when care is taken on by other services 24 h a day.

Carers should be privy to the following:

- condition of service user;
- medication information;
- advice on crisis management;
- information and resources;
- how to contact care co-ordinator;
- carers UK; and
- online help.

Carers offer a valuable resource; they know what is "normal" for the person they are caring for, what is in character and what their likes, dislikes, etc. are. Carers feel that being perceived as interfering is insulting. It could also be construed to be clinically negligent to not take into consideration the wealth of information they have with regard to caring for the service user. For a variety of reasons service users may be unable to speak for themselves, be unable to understand what is being asked or not fully appreciate the significance of the question they are being asked. These points are particularly salient when a service user is in an acute phase making them a poor informant. Good and informed information, from a carer, about the service user and their ability and levels of functioning when well is essential to obtain an accurate clinical impression and to assist positive and meaningful engagement.

Many carers reported negative engagement by proxy. They felt that there was little thought for their own situation by services with staff unable to recognise or appreciate carer burden and impact. There were examples reported where people were expected to drop everything at considerable personal costs, take time off work with ensuing threats to continuing employment, be a taxi service, and incur financial costs of fares, petrol and parking often at peak rate.

The role, time and involvement of the carer were often felt to be underestimated. Caring is not a 9-5 job. The way that services are configured can have an impact on both the service user and the carer. Short term treatments often do not have follow ups. Non-attendance or not seeking help can be mistakenly taken as a sign that the person is doing well rather than there is an issue and that they may have become depressed and lack the motivation to attend. This group may experience little help as the service users do not fulfil the eligibility for "crisis" care. This is further compounded as the service users often present to local GPs who may have limited expertise in mental health. Confusing jargon is also considered to be a hindrance to engagement and entry into services. Care pathways with complex service structures were reported to be difficult to understand. There is differing eligibility between the services and this feeds into uncertainty, as people do not know when they will move on.

Concerns were expressed by carers of service users discharging themselves prematurely and in some cases in the middle of the night. People in this situation are often sent home without support, the family not having been informed and care not being place. This can leave the person disorientated and distressed. There appears to be a lack of awareness of possible physical needs such as whether the person can get into their home, whether there is food there for them, etc. These issues are only exacerbated by not informing the carer about discharge.

Not all experiences are negative; a good care coordinator is often seen as the conduit to a more positive experience. However, this role varies between services and individuals and is dependent on the level of support or engagement that is offered. Carers commented that many difficulties could be avoided by services using a little common sense and listening to their valuable input relating to the service user.

Carers provided a number of other examples of the challenges they face and pleas for how they could be supported in these areas:

- Carer's beds are not provided by hospitals. Carers felt that in some cases provision of these is essential in order to ensure the daily care needs of the service user are met alongside the physical health care being received. They deemed their continued input was essential to enable and enhance recovery. "Hospital Passports" that travel with service users through their hospital journey and when they leave enable people to be genuinely engaged in their care. "The care and treatment becomes more personalised and dignified." A carer taking part in the focus group had extensive contact with general hospital care on behalf of the service user and appeared unaware of such scheme with the result that their caring responsibility appeared to have fully remained with them during hospital attendance.
- Aging carers was an issue with some carers being so concerned as to who would pick up their caring role that sadly they almost wished the service user would die before them.
- Time spent coordinating hospital appointments, particularly where several departments were involved, and length of waiting times was found to be problematic for carers. There was acknowledgement of the Hospital Passport and the work of Jim Blair at St George's Hospital as the way forward to overcome some of these hurdles.
- Day centres provide carers with time in their day to complete household and domestic tasks, but the coordination of day centre and transport timings make it difficult to attend anything outside the approximate hours of 10.30 am to 2.30 pm.
- Services use different labels and words to identify service user needs than carers who felt how they describe and see the person was right in their eyes and this should also be acknowledged by professionals.
- Family structure and changing roles when the service user's care circumstances change were not taken into account. There is a lack of acknowledgement of the emotional impact of these events and impact on people's working and social lives.

- Carers were not clear about the feedback mechanisms for problems they encountered with the service user's inpatient stay, e.g. concern about healthy eating and the supplement of take-away food.
- Carers want to learn how the system and/or treatment work and to do so they felt they need an appropriate means of access and a communication method. Carers are not always able to access computers to find out information and indeed some carers prefer other methods.

The participants highlighted a number of barriers to carrying out their caring role, e.g. obtaining funding for transport and attending meetings. The bureaucracy of form filling was often not easy to navigate on the service user's behalf. There is little support to meet government demands of the correct way to complete the forms. This can be a very onerous and difficult task for carers. Carers were often unable to provide the appropriate identification, as many of the cared for people do not have passports or driving licences.

Cuts in services have also increased the burden on carers. Carers feel "short changed" in that they are saving the government money and yet their role is becoming increasingly difficult due to lack of support.

## *Part 2*

*Solutions.* The next stage was to look at possible solutions and ways to support and engage carers. Participants were asked for examples of good practice that carers felt could be of potential benefit to others, and also for what they felt was needed.

"Developing a mental health guide for families and carers of people with intellectual disabilities" study (Spiller *et al.*, 2007) carried out six years ago identified key themes. These themes were also raised in the (recent) carer's forums highlighting the fact that the question regarding how to ensure that carers' needs are met has not been addressed (see the below list):

Themes common to family carers only:

- needs and support professionals (the right help, practical solutions, attitudes, advocacy);
- society (negative social life experiences, acceptance and understanding);
- recognition professionals (responsibility of caring, family devotion, determination, decision making);
- society (stigma/prejudice, isolation);
- information problem-solving strategies (ways of dealing with daily problems, seeking alternatives);
- promoting mental health for carers (confident/like-minded people, spiritual beliefs, respite); and
- new carers (attitude towards the guide, experience/knowledge).

A number of local resources were discussed which can assist people to break down barriers and provide access to education for carers. The focus should not only be on service and treatments but also about what can be done to assist carers at home and to help them to understand about the consequences of behaviour such as their own self-neglect and ways to address this. It would be helpful to have regular training courses and support networks available to inform and help carers so that they are aware of their rights, entitlements, and can have a better understanding of often confusing jargon.

It is important to have recognition and acknowledgment that there is more than one person on the (service user's) journey. There also needs to be a wider voice locally that feeds into problems associated with current government policies. It was felt by carers that there was a need to lobby the DWP about the oddities of the current system. Carers felt that their individual voices would not be heard and therefore they would welcome collective support from other organisations.

It is often difficult to understand how the different organisations interface. Some organisations hold carer's days and these can help both with this issue and also to make services more community orientated.

Carers identified their own strengths in providing care. Their persistence is needed to get what is required for the person they look after. This is often very stressful. Carers reflected that pets in the home environment can be calming and therapeutic when sometimes everything else can feel very chaotic.

Direct payments were seen as useful in enabling carers to employ people that they really trust and who know how to look after the service user.

Local (carer) groups had accessed local pharmacies and asked them to put advertisements for their carers group into pharmacy bags.

The carers who were knowledgeable about "Communication Passports" (Blair *et al.*, 2010) were really happy with how these work and how they ease the service user through the system.

### Wish list

The final part of the day was reserved to develop a wish list from carers of what changes they felt were necessary to achieve meaningful carer involvement:

- Greater and meaningful communication with staff.
- To understand that involvement of carers will improve outcomes and consistency of care for service users.
- To end geographical disparity of service provision.
- Seamless service for carers between organisations.
- Development of a standardised training/information pack for carers to assist them to carry out their role more effectively with the right information.
- Single provider of carer services to increase understanding/avoid accessing several sources of information.
- Inter agency co-operation to deliver community training to ensure meaningful carer involvement.
- Knowing who is in charge of supporting carers within organisations.
- Services users sometimes fall under "National Services" and are placed OOA and away from their primary carer. This then makes it difficult for carers to access local support. This problem needs to be addressed to ensure that carers get consistent support no matter where the person they are caring for currently resides.
- Carers would like to be able to rely more on a system of care. Carers often find that they have to be pro-active to get help and care for their loved one. This is exhausting, especially on top of the caring role.
- Introduction of pampering days.
- Lobbying to acknowledge that carers often care for several people with a combined total or more than 35 h. These should be reflected by making carer's allowance available to this valuable group.
- Care co-ordinator to be consulted by DWP before benefits suspended and carer kept fully informed.
- Acknowledgement that it is difficult for a carer to maintain a balance in their life and that help is needed to achieve this.
- To have a DWP mental health specialist.
- Reassurance by monitoring people not meeting the eligibility of (crisis) services to make sure they are not at risk "Catching people when they trip and before they fall".
- Specialist support to be available for certain groups, e.g. dementia care and intellectual disability.
- Respite for carers and their own holiday.

- Easier ways for carers to provide proof of identity for their loved one.
- Police training and further work on public safety particularly to develop further understanding of people with intellectual disabilities behaviours when accessing the local community where the behaviours may present differently from the rest of the community population.
- Information on how services work and better signposting for services.
- GPs to be better educated about MHLI issues.

## Summary and conclusions

The events offered an opportunity for staff to hear the experience of carers first hand. Below is a list of quotes that illustrate the issues which are described earlier. We heard examples of people “struggling to keep the person’s life on an even keel is to prevent stress for the person.” Carers often feel a that it is a large responsibility trying to run two lives and that it is difficult to balance the needs of both the carer and the service user in tandem.

Assumptions can often be frustrating and unhelpful with carers stating “You don’t know the situation unless you live with it.” Carers expressed the fact that each experience is individual and this means that it can be very isolating. Difficult situations were discussed with one carer saying “It’s inconceivable what I have to do, so I forget about it or I would go up the wall”:

- “They may answer the question but not with the correct answer.” Carers expressed concern about service users being left to answer questions on their own. This was particularly an issue in medical situations where it was essential for the professionals to have accurate information about the service user (who may not be in a position to impart this).
- “Some actions seem so obvious: like not to discharge him on his own.” Carers express frustration at services not being able to do things in a logical manner and with common sense.
- “Nowadays I don’t have the energy to do the things I love doing.” Carers talked about themselves and what they were missing out on which included hobbies and working lives, which in many cases isolated them further.
- “How do you know what you want because you don’t know what’s there.” Carers reflected on struggle to get the right services and input for the service user without a key overview of what was available.
- “We can’t get ill and we can’t go anywhere.” Carers worried about their own well-being and not being able to take time out for themselves to recover after illnesses, or take holidays. This issue was poignantly raised by older carers who were extremely concerned as to who would look after their relatives when they are not around.

This project found that despite geographical location (and other specific barriers) those carers’ needs both in and OOA were much more similar than perhaps expected. The report has highlighted the engagement of carers, unfairness of current government policy and specific issues that were important to the carers involved in the forums. Carers also strongly felt that they should be acknowledged and appreciated as a valuable resource of information about the cared for person.

Some of the issues that carers raised have been addressed with immediate effect particularly reducing the incidence of inappropriate discharge from hospital to the community. Projects in other areas of the trusts have sought to engage carers formerly at a very early stage in hospital admission resulting in a reduction of some of the carer and ward communication issues expressed in the forums.

As a result of the forums new methods of receiving feedback were looked at to avoid the issue of expecting carers to complete repetitive questionnaires. The project report will be sent to carers for comments.

The information gained from the forums should be disseminated as widely as possible across both statutory and voluntary groups to enable services to jointly and individually address the realistic concerns and needs raised through the carer forums. Such forums should



become regular events in MHL services. They should be also presented to carers in creative ways such as using technology such as e-mail rather than the expectation of continued face-to-face feedback which impacts on the caring day.

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