

# “More than 1 person on the Journey”: A Comparison of carers needs for service users cared for both in and out of area:

## Report to the Maudsley Charitable Trust

Heidi Emery

MHLD Placement Coordinator

Bridget Jones

Eddie Chaplin

Research and Strategy Lead, B&DP CAG

## Table of Contents

MORE THAN 1 PERSON ON THE JOURNEY”: A COMPARISON OF CARERS NEEDS FOR SERVICE USERS CARED FOR BOTH IN AND OUT OF AREA: .....	3
EXECUTIVE SUMMARY.....	3
<i>Background</i> .....	3
<i>Carer Events</i> .....	3
<i>Summary and Conclusions</i> .....	4
BACKGROUND.....	5
FACTS AND FIGURES: .....	7
TRIANGLE OF CARE .....	9
CARER EVENTS .....	11
ISSUES FACED BY CARERS:.....	12
ROLES OF CARERS:.....	14
EXPERIENCES OF CARERS: .....	14
EXAMPLES RAISED OF CARER CONCERNS.....	17
SOLUTIONS: .....	18
WISH LIST: .....	19
CONCLUSIONS.....	21
CARE IN AND OUT OF AREA.....	22
ACTIONS .....	23
BIBLIOGRAPHY .....	24

## Table of tables and figures

Table 1 Level of carer involvement.....	7
Table 2 Level of contact .....	8
Figure 1 Level of carer involvement.....	7
Figure 2 Level of involvement.....	9

# More than 1 person on the Journey”: A Comparison of carers needs for service users cared for both in and out of area:

## **Executive summary**

### **Background**

Throughout the course of the past 6 years the Mental Health Learning Disabilities (MHL) Placement Coordinator for the South London and Maudsley NHS Foundation Trust has been monitoring, reviewing and progressing the care of service users with forensic and complex needs in placements out of area. The placements are geographically disparate and range from the north to the south of England and to Wales, the variety of settings range from specialist community placements to hospital inpatient services across varying levels of security.

The OOA service has made a number of improvements in this time towards meaningful carer engagement however there is still a long way to go to achieve full and meaningful engagement across the whole of the carer group. From experience many carers have reported to feel “out of sight and out of mind” and are often isolated and left out of visits and contact.

### **Carer Events**

A series of carer events were held to:

Engage with carers

Look at the needs of this group

To see what could be done to promote more meaningful engagement across the whole group

Compare the needs of both the in and out of area groups and to see if they differed.

To see what was general to all groups and therefore could help to inform the local and national agenda.

The events consisted of focus groups and presentations and was held over 2 with invites issued to carers known to MHL teams, community social care teams and charitable organisations from the 4 boroughs of the Trust. The event also invited other key carer.

## **Summary and Conclusions**

From the consultation we found high levels of unmet need in a number of domains. These included; accessing information, being valued as a contributor by services, significant day to day challenges e.g. financing appointment, maintaining work/life balance, lack of formal support structures and lack of meaningful involvement. We found more similarities than differences between the issues faced by OOA and non-OOA carers. Nationally carer legislation applies to all but does not recognise clear differences in the challenges faced by carers such as sourcing funds to assist with visiting service users in their out of area placements.

The project cannot deliver on everything on the carers' wish list however; it can liaise with agencies, provide feedback and make recommendations in order to enable carers to care.

The Authors would like to thank the Maudsley Charitable Trust whose help and finance made this consultation possible. These findings will be disseminated to a wider audience via a specialist mental health journal which have commissioned the write up of this project: Emery, H, Jones, B and Chaplin E (submitted 2012) "More than 1 person on the Journey": A Comparison of carers needs for service users cared for both in and out of area, *Advances in Mental Health in Intellectual Disability*.

***“Family carers of people with learning disabilities have usually been carers for the lifetime of the person they care for. These carers are often described as having a lifetime experience of caring. This may mean they have been caring for 30, 40, 50 or more years. They have been through lots of different experiences as carers and had to cope with many changes.”<sup>1</sup>***

***“Caring for someone with a learning disability is from day 1 a whole life of caring”***

*Carer’s view expressed during a focus group 2012*

## **Background**

Throughout the course of the past 6 years the Mental Health Learning Disabilities (MHL) Placement Coordinator has been monitoring, reviewing and progressing the care of service users placed in placements other than the 4 boroughs covered by South London and Maudsley NHS Foundation Trust. These range from the north to the south of England and to Wales, the variety of settings ranging from specialist community placements to hospitals of varying security.

The work is led by Heidi Emery who is the out of area MHL Placement Coordinator for complex cases of people with mental health problems and learning disabilities placed out of area (OOA). In the 6 years in this role Heidi has made a number of improvements however there is still a long way to go to achieve full and meaningful engagement across this carer group. From her experience many carers have reported to feel “out of sight and out of mind”. They are often isolated and left out of visits and contact.

Throughout the course of the work the following concerns began to evolve:

- Historically the carers had not been included in the service user’s care due to physical distance of the placements between carer and service user or the history or circumstances that had led the service user to be placed far away from home.
- Carers were not clear of their roles once the service user had moved away.
- There appeared to be a lack of information as to how the carer should navigate often new systems such as those brought about by provision in the private sector.
- Some carers had been disregarded as their statutory role, mainly through fostering, had ended once the service user had turned 18 years old. Carers were therefore not being

consulted or involved about the service user's care because the statutory consultation period of 5 years under the MHA had ended. Though in many cases both the service user and carer perceived that roles such as 'Mum' were a lifetime commitment.

- Cost of frequently visiting placements that are over 10 miles away from home was an issue for carers who had limited access to funds and a lack of information and understanding of how to be reimbursed for costs associated with visiting and/or attending meetings.
- Some carers had very high and unrealistic expectations of how the service user could/should improve in their new placement.
- A small but significant number of service users had lost touch with their relatives and had no personal support and care to fall back on.
- Support for carers was lacking from the placements and/or the local health/social care services. This resulted in frustration; confusion and lack of understanding of the service user's care/on-going needs. In many cases being moved away from their carer caused the service user distress.

Contact with carers has been addressed by the introduction of pre and post visits Care Programme Approach (CPA) meeting to carers to promote engagement between families with the MHL D Placement Coordinator role acting as a conduit. This development has helped to signpost carers to get help, assistance and increased contact between the carer and the service user and the placement. Not everyone though has engaged, and this is often through choice e.g. anti services, relationship breakdown. This group are not forgotten and the placement coordinator has continued to gradually involve these carers at their own pace. The role of the out of area MHL D Placement Coordinator has been to ensure quality of care and to provide reassurance about placements. The latter point being particularly important in light of the recent report into abuse at Winterbourne View (Flynn 2012).

Many of the service users on the caseload have been out of area for a long time and have come to regard their placement, or at least the area it is in, as home. In some cases the placement coordinator take on a brokerage role that offers a choice between repatriation or staying in the area to which they have become accustomed whilst acknowledging the needs of the person and their family.

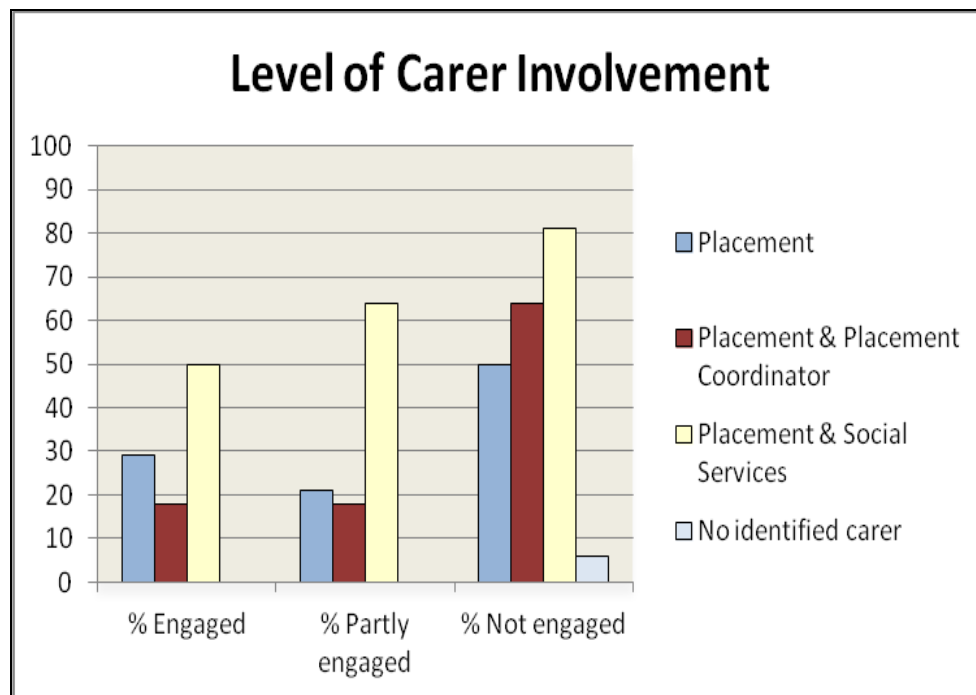
## Facts and Figures:

A snapshot of Carer involvement was captured in June 2010, see table 1 and figure 1 below:

**TABLE 1 LEVEL OF CARER INVOLVEMENT**

	Placement	Placement & Placement Coordinator	Placement & Social Services	No identified carer
<b>% Engaged</b>	29	18	50	0
<b>% Partly engaged</b>	21	18	64	0
<b>% Not engaged</b>	50	64	81	6

**FIGURE 1 LEVEL OF CARER INVOLVEMENT**



The placement coordinator in her day-to-day work uses a variety of measures to determine the progress of the service user group. Data collection in a recent audit projects reviewed the use of the HoNOS LD (Roy et al 2002). The HoNOS-LD illustrated low contact and fluctuating relationships when measured at 2 different points in time. See table 2. The question in the

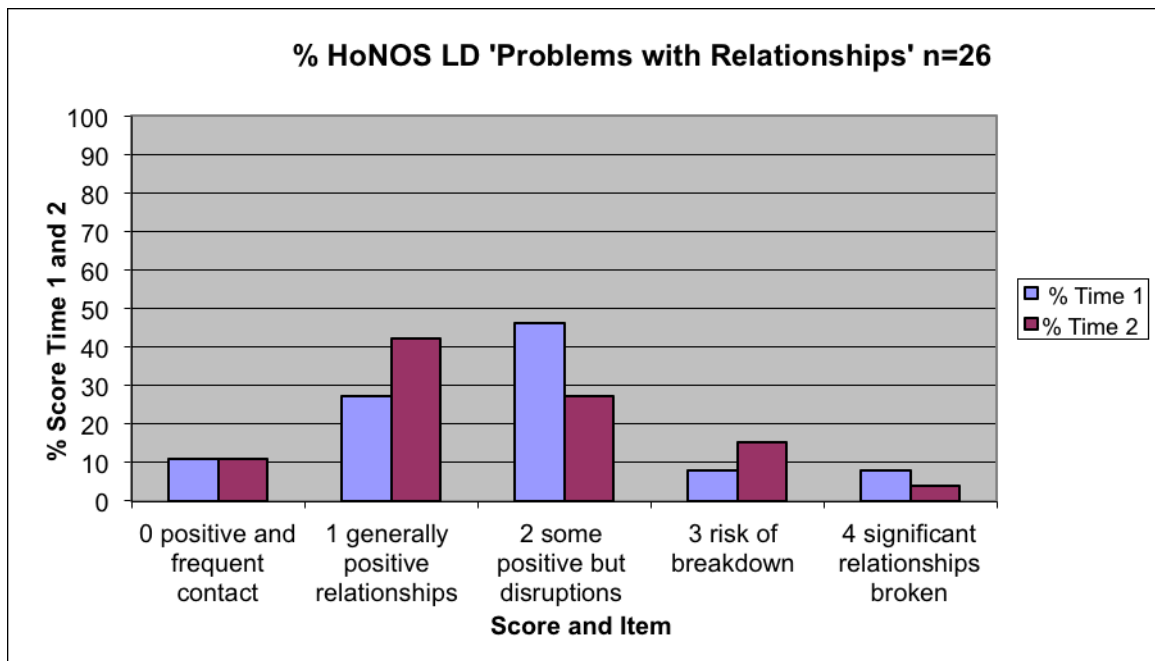
measure relating to carers is described for the rater as 'Problems with relationships' which 'Include the effects of problems with relationships with family, friends and carers (in residential and day / leisure settings). See figure 2. Therefore advising the rater what's a record e.g. 'Measure what is occurring regardless of cause e.g. somebody who is known to have good relationships may still display problems'.

**TABLE 2 LEVEL OF CONTACT**

<b>HoNOS LD Score and Item</b>	<b>% Time 1</b>	<b>% Time 2</b>
<b>0</b> positive and frequent contact	11	11
<b>1</b> generally positive relationships but some limitations in contact	27	42
<b>2</b> some positive but disruptions and worsening contact	46	27
<b>3</b> risk of breakdown or infrequent contact	8	15
<b>4</b> significant relationships broken down with no current contact	8	4



**FIGURE 2 LEVEL OF INVOLVEMENT**



Over a six-month period the scores for problems with relationships changed. Positive relationships were characterised by frequent contact remain the same at the two-time measurement points. Relationships described as generally positive at T1 increased in T2 whilst relationships that were described as disruptive decreased in T2. Score three increases at time two where a service user who scored four at time one was reunited with their relatives by the second rating. Overall these scores reflect how intervention with service users and carers can positively increase service user and carer relationships..

## Triangle of Care

More recently work with carers has led the Trust to adopt 'The Triangle of Care' Carers included: A guide to best practice in Mental Health Care'. This guide has also influenced this carers project. There are 6 key elements relevant to this service user group whether in acute or specialist residential care:

- Carers and the essential role they play are identified at the first contact or as soon as possible thereafter.
- Staff are 'carer aware' and trained in carer engagement strategies.
- Policy and Practice protocols re confidentiality and sharing information are in place.
- Defined post(s) responsible for carers are in place.

- A carer introduction to the service and staff is available with a relevant range of information across the acute care pathway.
- A range of carer support services is available.

A Carers project was set up by Heidi Emery through and funded by the Maudsley Charitable Funds to address the issues:

- Isolation of carers.
- Lack of information for carers, where there appeared to be a plethora of information but it did not appear to be coordinated to meet the carers needs.
- Impact on relationships between service users and carers/family members when circumstances change.

The project plan:

- To run 2 carers focus groups.
- To develop a “needs” questionnaire for those unable to attend the focus groups.
- To review needs of groups both in and out of area.
- The project anticipated objectives:
- To get carers more involved by contributing their knowledge and views directly to the individual care service user and more widely feeding back to the Trust to assist in improving the Trust’s services.
- To have carers’ needs and opinions listened to.
- To inform and increase understanding for carers and service users of both NHS and Private systems and pathways.

The project potential outcomes were as follows:

- Explore the feasibility for an OOA Carers support group
- Develop a carers’ strategy for MHLDD
- Ensure carers are aware of how to access health and social care organisations and that they understand procedures for putting in formal complaints.

- Ensure that information for carers is presented in a useable format meeting individual needs.

All aspects of the project were carried out with as much consultation with carers as possible. This process was started by attending the Behavioural and Developmental Psychiatry Clinical Academic Group's Service User and Carer Involvement Meeting. The purpose of this was to ask an established and involved appropriate membership what they thought were the issues that needed addressing. Many issues were raised in a short period of time and these provided questions for the focus groups. Points to address in the longer term were also raised alongside issues that the professionals involved had not considered/perhaps perceived before from the Carer and Service User perspective.

The group suggested that the following topics/themes should be addressed:

- Reflection time to capture carers' issues.
- To structure the day effectively to create an enabling environment
- A 'Do you know?' section on the services/support currently available for carers.
- 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.
- Record the number of Carers assessments that had taken place.

## **Carer Events**

The invitations to the focus groups, to be held on 2 days in late spring, were sent to the many carers known to MHLDD teams, community social care teams and charitable organisations of the 4 boroughs of the Trust. They were sent both directly and via community staff. The event, as well as focussing on the out of area carers, also invited other groups from the local area and national services. The reasoning behind this was two-fold:

Compare the needs of both the in and out of area groups and to see if they differed.

To see what was general to all groups and therefore could help to inform the local and national agenda.

The events were scheduled between 10.30 am and 14.00 hours, a learning from other Trust Carer events, in order to provide carers with the time required to care and access day facilities for the service user.

An Agenda was developed based on the consultation with the Behavioural and Developmental Psychiatry Clinical Academic Group's Service User and Carer Involvement Meeting, The event started with a brief introduction from the MHLD Placement coordinator commenting on observations of the carers of service users placed out of local boroughs. This was followed by a short presentation by a carer of a service user with a mental health problem. The rest of the agenda was kept loose to enable as much contribution as possible from the carers in their own manner. The day focussed on three main areas:

1. Issues faced by carers
2. Roles of Carers
3. Experiences of carers

The response to the invitations however was limited and the attendance low; however some carers responded that they could not attend but wished to receive copies of the reports in order to contribute their views and issues. There were also changes in attendance due to last minute needs of carers to carry out their role. An older adult carer opted to bring her son with her as the coordination of day centre and attending the event proved logistically problematic for them. There was no attendance or response from carers of service users currently placed out of area. The consultation was therefore extended to access a charitable group and a Trust carer event held in Carers Week totalling 4 main sources of feedback and information.

### **Issues faced by carers:**

Similar issues were raised in each of the events. The biggest obstacles appeared to be trying to navigate the present system and problems relating to the current Government policy on caring and incapacity. We found carer experiences were outside of the expected scope of their role as defined in policy and benefit agencies, neither of which appeared to be in touch with the reality people were facing on a day-to-day basis. There was acknowledgement that "Although there is already information available about caring for someone with a mental health problem, there is very little written for families and carers of people with intellectual disabilities." <sup>2</sup>

Most carers stated that they found it difficult to keep up with changes both to policy and to the benefit system. Carers are often older adults and often support more than one person. This support may 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 is £58.45 per week. This is reduced by the amount of certain other benefits, including State Pension that the carer might get. 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 hours 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 hours per week of supervised study is not entitled to Carer's Allowance. This 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.

Many carers did not know that they were entitled to have regular carer assessments and the administration of assessments was sporadic.

The participants highlighted real examples which increased the challenge and expectation of their day-day caring:

Funding for transport costs for visits and for attending meetings.

Systems of form filling are not easy to navigate on the service user's behalf and there is little support to meet departmental demands of the correct way to complete the forms.

Providing the appropriate identification for a service user who only has a birth certificate and freedom pass when systems dictate photographic identification of a passport or driving licence.

Service cuts in particular had not been replaced by any other services which the carer could view as helpful to give them a break from caring.

Carers felt 'short changed' in that they were saving the government money yet their role was becoming increasingly difficult due to lack of support. Sometimes simple adjustments would enable them to fulfil their roles more efficiently.

Carers also expressed the view that services should listen to and consult with them on many levels as stated in the government policy.

Carers commented that consultation events often felt like a paper exercise and they expressed frustration that although it took them a considerable amount of time (of which they have little spare outside their caring role) to give their views and they did not then receive any feedback on the day or afterwards as to how the information given was being taken forward. These issues decreased carers' motivation to attend events and to give feedback on issues. Carers spoke with regard to problems adhering to systems and rules of policies and procedures. Carers did not appear to have a resource that could assist them with this.

## **Roles of carers:**

The position of carer is multifaceted with the role changing with caring for someone an evolving situation. The carer has responsibilities with the wider family, feeding the family, gathering information as well as supporting the service user. Carers are a valuable resource and have expert knowledge regarding the needs of the person for whom they are caring. There is a need for the clinical teams to not only involve carers but to appreciate that they are an important source of information relating to the service user. Good communication with carers will aid in the provision of the best and most appropriate care for the service user.

The role is discussed further below using personal experiences of carers.

## **Experiences of carers:**

Some carers find it is a challenge to even be involved once when their cared for person is receiving services. Carers often described feeling neglected and that patient confidentiality is given as a reason for non-engagement.

Carers commented that when there was a response it could be so general it offered little reassurance such as “They are fine”. This was particularly difficult for carers of service users recently placed into in-patient care. It was commented that it was difficult to go from being responsible for caring for someone 24 hours a day to in-patient care and receiving very little information. “The sharing of information may be difficult, but is often crucial to the ongoing wellbeing of both patients and carers. If carers are excluded from important discussions and decisions involving the patient, this can have serious practical, financial and personal consequences for both the carer and the patient. Not being involved increases feelings of isolation, grief and loss which are common to many carers.”<sup>3</sup>

Carers at the events described feeling not only neglected but also as though they were intruding with the professionals who were now caring for the service user e.g. ward staff. It was reported by carers that it is often difficult to have access to member of the medical team for queries. Patient confidentiality and the Data Protection Act were often given as reasons for non-engagement with carers. 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 that would breach confidentiality. 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 reported difficulty in accessing the following:

- Condition of service user
- Medication information
- Advice on Crisis management
- Information and Resources
- How to contact care co-ordinator
- Carers UK
- Online help

Carers offer a valuable resource; they know what is “normal” for and to the person they are caring for, what is in character and what their likes, dislikes etc. are. Carers do not want to interfere but want to offer advice in particular when the person is unable to do so for a number of reasons such as not being able to understand what is being asked, not understanding the

significance of the question. Knowledge of the person's abilities would greatly assist engagement with services and with ensuring that the service user received the best and most appropriate care. For example, service users with poor literacy skills are unable to fully participate or to understand/utilise written information provided about their care. The carer can often assist in this area either by direct input or advising the team on how the service user best receives information crucial to their care

Conversely, there is also a flip side that people are sometimes engaged by proxy, without their own needs being considered by services. Staff do not appear to be able to recognise carer burden and impact. There were examples where carers were expected to drop everything at considerable personal costs, take time off work with ensuing threats to ~~the~~ continuing employment and incur financial costs of fares, petrol and parking often at peak rate. The role time and involvement of the carer were often felt not to be considered and at best underestimated. Caring is not a 9 to 5 job.

The way services are configured can also have an impact on both the service user and the carer. Often with short-term treatments there is no follow up. Non-attendance and lack of active help seeking is often taken as a sign that the person is doing well rather than there is an issue that they may be becoming depressed and lack the motivation to attend. Often this group of carers will get no help, as they 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 and learning disabilities.

More than one experience was expressed where a service user discharges themselves prematurely, in some case in the middle of the night. People can be sent home without support, the family not having been informed and care not being in place., This can leave the service user disorientated and distressed. This lack of awareness of possible physical needs e.g. does the person have food, can they get in etc is compounded by not contacting carers who are not only able to respond but have asked to be kept informed at all times.

Another issue was navigation of care pathways and systems with complex service structures and confusing jargon can also hinder entry into services. Carers do not necessarily understand such systems and pathways, let alone which one will help them to obtain the rights support/assessment for both the service user and themselves in order to get their full needs addressed. This feeds into uncertainty often with people not knowing when they will move on with their care, such as leaving hospital.



Not all carer experiences are negative; a good care coordinator is often seen as the conduit to a more positive experience. However carers identified that this role is variable between services or individuals as to what level of support or engagement they offer. 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 hours a day. Carers commented many difficulties could be avoided by services using a little common sense and listening to their valuable input relating to the service user.

## **Examples raised of carer concerns**

Carers at the events held and attended provided a plethora of examples of the challenges they face and pleas for how they could be supported in these areas which are listed below:

- Carers' beds are not provided in general 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. There are good systems such as 'hospital passports', which "enable people to be genuinely engaged in their care as the passport travels with them through their hospital journey as well as when they leave. As a result, people's care and treatment is more personalised and dignified." However, 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 a scheme and 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 they sadly 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 scheme 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 2.30pm.

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 the events leading to this change and the effect it has 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 works and to do so they felt they need an appropriate means of access and good communication methods. Carers are not always able to access computers to find out information and indeed some carers prefer other methods.

## **Solutions:**

The next stage of the process was to look at finding solutions. Participants were asked for examples of both good practices that they knew about that they felt could be of potential benefit to others, and also for what they felt was needed. A number of local resources were discussed e.g. Carers Lewisham and Lambeth Carers Hub, which can assist people to break down barriers and provide access to education for carers (in Lambeth). The main points from these discussions are listed below:

The focus should not only be on service and treatments but also about what can be done to help at home e.g. understanding about the consequences of behaviour such as self-neglect and how to address this.

There needs to be regular training courses and support networks available to inform and help carers so they are aware of their rights, entitlements, and can have a better understanding of often confusing jargon.

It is important to have a good understanding of the service user's journey and recognition and acknowledgement that there is more than one person on that 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 Department of Works and Pensions about the oddities of the current system. Carers felt that their individual voices would not be heard and therefore 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.

Carers had also managed to access services that they felt were good such as the GP and day centre services which they'd been involved in development of and appeared to see more value in that service due to their involvement in its development.

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

Local carer groups had accessed local pharmacies putting advertisements for their carers group into pharmacy bags.

The carers who were knowledgeable about 'Communication Passports' were really happy with how these work and how they ease the service user through the system.

### **Wish list:**

Finally we asked for a wish list of how carers would like to be involved in an ideal world. This is set out below:

- Greater and meaningful communication with staff
- To end geographical disparity in what is available and how services respond
- Seamless service for carers between boroughs and organisations

- Development of a standardised training/ information packs 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.
- Knowing who is in charge of supporting carers within organisations
- Service users sometimes fall under “National Services” and are placed out of area 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 hours. 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 help 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, learning disability
- Respite for Carers and their own holiday
- Easier ways of proof of identity of the service user.
- Police training and further work on Public Safety particularly to develop further understanding of the behaviours of people with learning disabilities. When this group accesses the local community their behaviours may present differently from the rest of the community population. This needs to be recognised and appreciated.
- Information on how services work and better signposting for services
- GPs to be better educated about mental health and learning disability issues

## Conclusions

Carers provided their views and it is important to hear in their words what the caring experience can be like for them:

“Struggling to keep the person’s life on an even keel is to prevent stress for the person”. Carers often feel that it is a large responsibility trying to run two (or more) lives and that it is difficult to balance the needs of both the carer and the service user in tandem.

“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.

“It’s inconceivable what I have to do, so I forget about it or I would go up the wall” Carers talked about some difficult situations they had to deal with and were very matter-of-fact about how they focus on the job at the time.

“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 including hobbies and working lives. In many cases this isolated them further.

“How do you know what you want because you don’t know what’s there”, carers reflected on their struggles 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 for illness and recovery or to 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 group of carers identified issues that 6 years earlier were recognised as key themes from the Developing a Mental Health Guide for Families and Carers of People with Intellectual Disabilities study:

'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)  
New carers (Attitude towards the Guide, Experience/knowledge)' <sup>2</sup>

The fact that these themes were also raised in the (recent) carers' forums highlights the fact that the question regarding how to ensure that carers' needs are met has not been addressed.

## Care In and Out of Area

The project and resource are not currently broad enough to establish any distinct differences between the needs of carers for service users placed both in and out of area. However informal conversations through case work and carer contributions to CPA meetings would suggest that there are a wide range of similarities between the two groups in relation to government policy but clear differences in challenges such as sourcing funds to assist with visiting service users in their out of area placements. Information provided to carers varies widely and has been dependent on what is provided by individual out of area placements and in most cases the carer is included and kept up-to-date. The more wider issues for out of area carers appears to be dealing with what happened to put the service user and their family in the position of being away from each other.

## Actions

The project cannot deliver on everything on the carers' wish list however; it can liaise with agencies, provide feedback and make recommendations in order to enable carers to care.

The actions are currently limited to the service from which the project originated:

- Visits should continue to Lewisham, Southwark and Croydon Carers Groups for mental health and learning disabilities to reach the wider group and to update on progress/continued consultation
- The write-up should be sent to all participants to and those who expressed an interest but couldn't attend to widen the inclusion of carers.
- The MHL D service should continue to work with a core carer group face to face or by email to reach consensus in to develop some of the ideas/common themes.
- Carers should be invited to work with the MHL D service to ensure their needs are met
- Improved staff training within SL a M and across King's Health Partners that embraces carer expertise and aims to facilitate better communication with carers, particularly the issue of staff understanding "patient confidentiality" with regard to carers.

## Bibliography

Below is a list of works cited or referenced during this report.

Blair, J, Glaysher K and Cooper, S (2010) Passport to Health, <http://www.intellectualdisability.info/how-to../passport-to-health> September 2010

Department of Health (2009a) Supporting Learning Disability Partnership Boards to implement the National Carers Strategy, 2009, Department of Health, [www.doh.gov.uk](http://www.doh.gov.uk) <sup>1</sup>

Department of Health (2009b) New Horizons: a shared vision for mental health, London: Department of Health.

Department of Health (2004) Commissioning service close to home: Note of clarification for commissioners and regulation and inspection authorities. London: Department of Health

Developing a Mental Health Guide for Families and Carers of People with Intellectual Disabilities. Spiller, A. Jane, M. Holt, G. Joyce, T. Hardy, S. Bouras, N. Journal of Applied Research in Intellectual Disabilities, Mar2007, Vol. 20 Issue 2, p77-86 <sup>2</sup>

Flynn, M. (2012). South Gloucestershire Safeguarding Adults Board Winterbourne View Hospital A Serious Case Review.

National Mental Health Development Unit, 2010. The triangle of care: carers included: a guide to best practice in acute mental health care. Publisher: London: Patient Information Centre,

Northumberland Tyne and Wear (2012) "Commonsense Confidentiality", September 2012

Roy, A., H. Mathews, et al. (2002). "Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)." British Journal of Psychiatry **180**: 61-66.

Roy, A., H. Matthews, et al. (2002). "Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD): glossary for HoNOS-LD score sheet. British Journal of Psychiatry, **180**: 67-70.



Royal College of Psychiatrists "Care and Confidentiality in Mental Health

<http://www.rcpsych.ac.uk/campaigns/partnersincare/carersandconfidentiality.aspx><sup>3</sup>

South London and Maudsley NHS Foundation Trust (2010) Family and Carers Handbook