Healthwatch Oxfordshire

Update for the Health and Wellbeing Board – 17<sup>th</sup> July 2014

## 1 Delivery of Healthwatch Oxfordshire

**1.1** The original grant for the delivery of Healthwatch Oxfordshire (HWO) was awarded to Oxfordshire Rural Community Council (ORCC) until 31st March 2014. Following the subsequent tender process the grant for the next two years was awarded to a Community Interest Company called EASI Healthwatch CIC which was specifically created to act as a vehicle for the delivery of HWO. EASI Healthwatch CIC took over responsibility for the delivery of the service from 1st April 2014 with arrangements made to complete the transition of the service from ORCC to the CIC. All members of the Board of Healthwatch Oxfordshire were appointed as Directors of the CIC.

1.2 The first chairman was Larry Sanders. He has recently retired from the chair, having given HWO an excellent start. In his place the HWO board has appointed Jean Nunn-Price as Chairman and Dermot Roaf as Vice Chair for the next few months.

## 2 Chief Executive

**2.1** David Roulston was appointed as an interim Chief Executive in November 2013 pending the recruitment of a permanent successor and stood down on 27<sup>th</sup> June 2014. The Board has appointed Rachel Coney, currently Assistant Director of the CCG, as Chief Executive from 21 July 2014

## 3 Project Fund

**3.1** A project fund of £30,000 was established by Healthwatch Oxfordshire to support project work and research into different areas affecting people in respect of health and social care. The purpose of the fund is to enable HWO to better understand the experiences and needs of people in Oxfordshire and to identify good practice and areas for improvement in local Health and Social Care services.

3.2 The Project Fund is overseen by a sub-committee of the HWO Board and projects funded in the last financial year included:

3.3 Research in partnership with the Patients Association into people in Oxfordshire's experience of access to GPs.

3.4 Research by Oxfordshire Family Support Network into the health service experiences of people with learning disabilities and their families.

3.5     Research by Oxford Asian Women's Project into the health and social care experiences of Asian women in Oxford with a particular focus on primary care, mental health and domiciliary care

3.6     Research by Oxford Mental Health Forum into young people's perception of the information available to them about mental health support services.

3.7     Research by Community Glue to provide information and gather perspectives from a range of organisations about the introduction of Personal Health Budgets based on the personal experience of service users and carers, projects in other parts of the country and evaluations.

3.8     A project with Sign Lingual to explore the underlying communication issues affecting deaf people in accessing health and social care services.

3.9     A project by My Life, My Choice to explore the experiences of people with learning disabilities of their healthcare treatment at their local GP surgery.

3.10    Partial funding support for a Quality of Life survey to be undertaken by Oxford City Council's neighbourhood team.

3.11    The reports arising from the above projects are at different stages of completion. The first reports published arise from the projects conducted by Oxfordshire Family Support Network, Oxford Mental Health Forum and My Life My Choice. Some of the findings and details arising from these reports are highlighted later in this report for consideration by members of the committee.

**4       Research into the Healthcare Experiences of students of Oxford University**

4.1     As Board members will recall HWO commissioned a project last year to collect intelligence about Oxford University Students' experience of and impact on local publicly funded Health Services.

4.2     This involved a survey of 317 Oxford University students in November 2013 with a report subsequently compiled in February 2014 which was shared with Oxford University Student Welfare and Support Services Director, Oxford University Hospitals NHS Trust (OUHT) and Oxfordshire Clinical Commissioning Group (OCCG).

4.3     There were 4 main findings from the report:

4.3.1   High usage of A and E services –a surprisingly high number of students surveyed (13.88%) claimed to have used A&E services whilst at Oxford. Of particular concern was that over 20% of males surveyed had used A and E services.

4.3.2   Problems of access for international students: In comparison with UK students problems with knowing how to access public services was far more prevalent

amongst international students. More than half of the international students surveyed had no idea how to access listed health services (such as GPs and the 111 service) and the numbers of international students using services was lower. This provided a strong suggestion that information about local health services for international students is inadequate and accordingly they do not know how to properly use services.

4.3.3   Mental health services: From a comparison of students' perceptions of quality and access to the services they used, mental health services came out lower than their perception of other health services. It also came out as more polarised with many responses extremely positive but also many negative responses. The research recognised that further research needs to be undertaken concerning the different types of mental healthcare provision and how improvements could be made.

4.3.4   Centralisation: each college at Oxford provides certain health services such as a privately employed nurse and NHS GPs present once or twice a week. However the system is decentralised with no college mandated to do anything and little or no centralised authority or provision for student healthcare. This came up both in the analysis of current services and issues surrounding this were raised in many of the personal comments made by respondents.

4.4   OCCG have conducted a further analysis of student data following receipt of the report and this correlates with the findings concerning the demands placed on the A and E service

4.5   A follow up study has been undertaken in conjunction with the Student Consultancy as a more qualitative analysis looking in greater depth at students' experiences of A and E and mental health services. This report is at the stage of being finalised and will be issued for comment shortly.

**5      Research focus area 1 – Oxfordshire Family Support Network**

5.1   The purpose of this project and associated report was to contribute to the debate about how extremely vulnerable people with learning disabilities, autistic spectrum disorder and mental health needs or challenging behaviours can be better supported and safeguarded by providing information, advice and support to their families. In order to compile the report three focus group meetings were held with local families (one of which was held with Bill Mumford, the Director of the National Winterboune View Joint Improvement Programme) and a series of focussed interviews were undertaken.

5.2   There are a range of findings with regard to the commissioning of the services provided for this group and understanding the needs of the families and young people using these services. The full detail of recommendations arising from the report can be found in appendix 1 to this report.

5.3     The report highlights the failures in respect of the current system and calls on local commissioners to work with families and services users to create services which meet their needs by working with them as 'experts by experience'. Particular areas which require more detailed consideration include the following:

5.3.1   The problems associated with the transition between children and adult services.
5.3.2   The frequent failures to provide information and support to enable families to make informed choices about which services to use.
5.3.3   A proposal to undertake scoping work on developing a peer-to-peer network of support and advocacy for families with the suggestion that Oxfordshire could be a potential pilot area to test out a peer advocacy and support model.
5.3.4   The importance of services and commissioners working with families to seek solutions rather than perceiving families as part of the problem.

5.4     HWO will wish to see progress in changing the methods of commissioning in response to the findings outlined in this report and the report has highlighted a range of issues that require further scrutiny.

## 6      Research Focus Area 2 – Oxford Mental Health Forum

6.1     The report associated with this project arises from an extensive online survey to find out about the information and support available on mental health for young people in Oxfordshire. The survey collected a total of 406 responses from a range of sources which included schools, young people (aged 16-25), professionals and parents/carers.

6.2     The executive summary and recommendations from the report can be found in appendix 2 to this report. Particular areas addressed in the report include the following:

6.2.1   There are many information gaps for young people about mental health issues and it is important that this is addressed through a focus on early intervention and increasing mental health awareness and understanding amongst young people, their parents/carers and the staff who support them.
6.2.2   Many of the people surveyed highlighted problems with long waiting times to access mental health services.
6.2.3   Young people need practical help and support in addressing mental health related problems.
6.2.4   A very high proportion of the parents/carers who took part in the survey had concerns about their child's mental health and they experienced difficulties in gaining access to the information and guidance and support they needed.

6.3     HWO has received confirmation from OCCG that they are starting work this year to review the way that services for children and young people are commissioned and that the report will help inform this approach. Oxford Health has also provided a detailed response to the report highlighting actions which are being taken on a

range of fronts to address some of the matters covered in the report which include the following:

6.3.1   They have been awarded the contract to provide school health nursing from April 2014 and the model to be adopted will mean that from September 2014 there will be a School Health Nurse (SHN) in every state school in Oxfordshire.

6.3.2   The SHN will have an integral role in ensuring that a health plan is developed in each school to include the mental health and wellbeing of students.

6.3.3   A pilot project initially involving three schools is about to be run to put the Primary Child and Adolescent Mental Health Services (PCAMHS) into secondary schools on a weekly basis. This will enable schools to book young people into sessions as well as staff being able to discuss any concerns they may have about mental health of pupils. A move is also underway to enable 16 and 17 year olds to self-refer to the service this year in addition to the arrangements for GPs, schools, children's centres and youth workers to refer people to the service.

6.3.4   Emergency and urgent referrals are being seen within the respective targets of 24 hours and 7 days but there is an acknowledgement of an increase in waiting times for routine referrals to the service.

6.4   The report mirrors evidence found elsewhere of an increase in demand for services and increased waiting times.

## 7   Research Focus Area 3 – My Life My Choice

7.1   The report arising from this project was compiled based on the results arising from facilitated discussions with eleven self-advocacy groups across Oxfordshire.

7.2   The recommendations arising from the report can be found at appendix 3 of this report. Particular areas addressed in the report include the following:

7.2.1   People with learning disabilities suffer notable health inequalities when compared with the population as a whole. A recent inquiry into the premature deaths of people with learning disabilities found that three times as many people with learning disabilities die before the age of 50 compared to the general population.

7.2.2   Annual health checks represents a significant opportunity to address this inequality however in Oxfordshire only 45% of those eligible had a health check in 2012/13 compared to the national average of 53%. The target set by Oxfordshire's Joint Health and Wellbeing Strategy was 50% for 2012/13 and 60% for 2013/14 but the report raises concerns about whether this target will be met.

7.2.3   There is a general lack of knowledge about learning disability amongst those working in healthcare services. This needs to be addressed and people with a learning disability given respect as 'active protagonists in their own healthcare'.

7.3   The report also adds to the body of evidence that is being compiled in relation to access to GPs by people in Oxfordshire.

## 8   Initial Priorities Set by Healthwatch Oxfordshire

8.1 The following four initial priorities for attention were set by the Board of HWO:

- Access to GPs
- Setting up representative groups for relatives in care homes
- 15 minute visits in domiciliary care
- Whistleblowing

8.2 In order to explore the issue of GP access a survey was conducted throughout Oxfordshire and over 830 responses received back. The report arising from this report is being finalised and is due for publication at the time of compiling this report.

8.3 HWO is in discussion with a range of different parties about the establishment of representative groups for relatives in care homes with a view to compiling a subsequent best practice guide to promulgate the establishment of such groups more widely in care homes.

8.4 HWO welcomed the additional £800k which has been found to do away with 15 minute visits for personal care. HWO has been in correspondence with the County Council regarding the implementation of this new approach and will be designing a study for later in the year to look at the impact of the change in policy. Among the points arising from this correspondence are the following points:

8.4.1 An instruction has been issued to County Council staff asking them to stop commissioning 15 minute home care visits for undertaking certain personal care tasks.

8.4.2 A recent analysis of their records has indicated that about 770 people a receiving a 15 minute visit of some form. A review is being undertaken to establish how many of these visits involve some form of personal care.

8.4.3 The County Council will be writing to all clients who receive a 15 minute visit to book a review with them.

8.5 HWO will be holding a whistleblowing conference in October/November 2014. As mentioned previously the reason for HWO setting this priority was to seek reassurance that whistleblowers in health and social care services in Oxfordshire are being actively listened to and their concerns are acted upon. 4 high profile whistleblowers will be speaking at the conference including Helene Donnelly who is a former A and E nurse who was called to give evidence at the Francis Enquiry. HWO hopes that the conference will attract a wide range of attendees and support its objective for delegates to increase the awareness of whistleblowing and seek to put in place actions which will enable staff to speak out safely.

9 **Engagement with the voluntary sector**

9.1 HWO is arranging a conference to bring together representatives from the voluntary sector to consider the range of issues faced in the commissioning and

delivery of health and social care locally and to help it shape its future priorities in respect of areas requiring attention in respect of the commissioning and delivery of health and social care.

## 10      Care.data

10.1    HWO contacted Healthwatch England earlier in the year regarding concerns which had been raised by patients and other patient groups regarding the introduction of the care.data programme. This echoed concerns which had been raised by a range of other local Healthwatch organisations and Healthwatch England subsequently raised concerns about the failure to adequately inform the public about this measure. HWO has welcomed the use of Healthwatch England's statutory powers to raise such concerns and the subsequent delay of the programme to enable better engagement and information for members of the public.

10.2    HWO has issued a preliminary position statement highlighting particular concerns it has about the programme together with suggested actions which could be taken in response. We have also arranged a public debate in Oxford on 10th September on the subject of care.data to enable the public to become better informed about the programme and raise issues of concern for clarification. The debate will be attended by representatives from Medconfidential and NHS England and Dame Fiona Caldicott has agreed to chair the discussion.

## 11      Additional matters for consideration

11.1    HWO has received expressions of concern about the status and future use of community hospitals. These include the ongoing debate regarding the status of the Horton General and the recent decision to close 10 community beds at Didcot Community Hospital. This issue has been raised in the context of the use of community hospitals to address issues like delayed discharges, the impact of Winter pressure and the desire to deliver care 'closer to home' as envisaged in OCCG's future strategy. The Health Overview and Scrutiny Committee is due to consider community hospitals at its meeting on 18th September and HWO has encouraged the committee to include such considerations as part of its scrutiny.

11.2    Finally it has come to the attention of HWO that the current policy in Oxford is that people sleeping rough in the city who are admitted to hospital are not being prioritised for hostel beds upon discharge. We understand that this is based on a priority being placed on reducing the number of rough sleepers on the streets in Oxford but are concerned (amongst other considerations) this could displace people who were in hostel accommodation prior to being admitted to hospital and leaves them at risk of a return to the streets following discharge from hospital. This is of concern with regard to the future health needs of those affected but also in the light of emerging evidence contributing to Healthwatch England's Special Inquiry looking at the subject of unsafe discharges from hospitals and care homes.

11.3 HWO recognise the complexities and interplay of homelessness, delayed discharges and the severe lack of accommodation within the city however we feel that this issue should be the subject of further scrutiny given the potential issues raised in respect of increased risk and the challenges raised for healthcare staff in discharging people safely from their care.


Appendix 1 – recommendations arising from the report compiled by Oxfordshire Family Support Network

Recommendations for Healthwatch Oxfordshire

1. Healthwatch uses its powers to verify the quality and safety of local provision on behalf of some of the most vulnerable Oxfordshire people with learning disabilities, mental health needs and challenging behaviours

2. Heathwatch continues to hold Oxfordshire County Council (OCC) and Southern Health accountable for the commissioned services and keep the local Winterbourne Concordat on track

3. We recommend that Healthwatch particularly monitors what is happening to young people under the age of 25 - and especially those who are under 18 years of age

4. Careful monitoring of the use of physical restraint

5. Healthwatch uses its role to monitor health inequalities for people with learning disabilities, mental health needs and challenging behaviours who may also have a dual diagnosis of autism

6. Ensures families are signposted to advocacy support

Recommendations for Oxfordshire County Council

a) Commissioning

1. Oxfordshire County Council must commission services for people with learning disabilities, mental health needs and challenging behaviours that are safe and of good quality - indeed that Oxfordshire can be proud of. The global principles of open contracting should be employed.

2. OCC must ensure that commissioners have a close working relationship with providers that enable them to be sure of how the providers are performing. The key performance indicators need to be robust, meaningful and with a focus on providing personalised approaches with positive outcomes for people using these services

3. OCC should work with families and people with learning disabilities to define what the characteristics of good services should be like and to identify innovative approaches and locate gaps in commissioning so that people are not held in secure units simply because there is no opportunity to move on

4. Work with experts by experience with learning disabilities and family carers to monitor quality and develop good training for staff

5. Crucially, OCC should not allow providers to continue providing services on the basis that they are "too big to fail" as it is simply too risky for vulnerable people with learning disabilities

6. The recent experiences of failing services demands greater local accountability from service providers in the future

b) Understanding the needs of young people

1. Work closely with NHS England and Oxfordshire Clinical Commissioning Group to identify what is happening to young people and where they are so that no young person goes out of county without close monitoring and regular follow up

2. Ensure that Southern Health has a transition policy in place as a matter of urgency

3. Use health checks at 14 as a minimum to aid earlier identification of young people with mental health needs and behaviours that challenge

4. Develop a menu of local provision that is suitable for these young people, including respite care and residential treatment facilities. This requires highly skilled staff that can use a range of interventions, including Positive Behavioural Support and also community-based facilities that enable young people to develop skills, meaningful activities and that support families effectively

c) Using the SEND Reforms to drive change

1. Improve the Local Offer under the Special Educational Needs and Disability (SEND) Reforms so that young people with learning disabilities and autism and their families are supported well through transition to adult services when they have mental health needs and challenging behaviours

2. Use the Single Assessment Education Health and Care plans to capture the needs of vulnerable young people with particularly complex needs and put action plans in place to support them at the earliest possible stage

3. Ensure that the Local Offer of information gives clear information about the appropriate use of the Mental Capacity Act and Best Interests meeting and that families are informed about the planned reforms to Deprivation of Liberty Safeguarding

Recommendations for Oxfordshire Clinical Commissioning Group (OCCG)

1. OCCG explores with partners the need for an in-patient facility for under 25s and works with families and people with learning disabilities to commission innovative support

2. Works with experts by experience to improve training in the awareness of the needs of people with learning disabilities, challenging behaviours and mental health needs

3. OCCG ensures better training in learning disability and mental health for GPs and in the Mental Capacity Act

4. To similarly provide better training in the appropriate use of the Mental Capacity Act for nurses and other clinical staff

5. Ensure that there is a clear understanding of person-centred approaches and that these are embedded in clinical practice across Oxfordshire

6. Commission for person-centred, quality support that leads to better outcomes including development of a specialist transition nurse role

7. Development of enhanced models of crisis care support

Recommendations for NHS England

1. Ensure the commissioning of high quality services that are designed and commissioned with the involvement of people with learning disabilities and their families using the global contracting principles referred to in the full recommendations

2. NHS England to work with Local Authorities and local Clinical Commissioning Groups to ensure that the local community know who are supported in secure units, where they are and their ages. We want to see unstinting efforts made to provide effective treatment and support that is subject to close local scrutiny by Healthwatch, CQC and local safeguarding services. We recommend that person-centred services are developed in local communities using highly skilled staff as part of the menu of support

3. Ensure better information transfer between in-patient and community-based health and social care services including integrated IT systems. A particular weakness was identified when information needs to be transferred between private hospitals and NHS facilities.

Appendix 2 – Executive Summary and Recommendations Arising from Report Compiled by Oxford Mental Health Forum

Executive summary

An extensive online survey was carried out to find out more about the information and support available on mental health for young people in Oxfordshire. The survey collected responses from schools, young people (aged 16-25), professionals, and parents/carers. There were 406 responses to the survey in total, which included feedback from 15 schools, over 300 young people, 44 professionals and 21 parents/carers. The following commentary provides the findings from the research, along with key recommendations for each group.

Overall core recommendations:

For secondary school head teachers and mental health providers:

▯ Provide a greater focus on early intervention and increased mental health awareness and understanding.

In particular:

- Introduce regular talks on mental health in schools;

- Increase the training and resources to better equip and support staff in schools.

Actions: Oxford Mental Health Forum and Healthwatch Oxfordshire to contact head teachers and local mental health providers to work collaboratively to roll-out mental health talks from local mental health support groups/providers (such as the Samaritans, Oxfordshire Mind, Oxford Health NHS FT) in all secondary schools in Oxfordshire and help to identify and address training and resource gaps to better equip and support staff in schools.

For local commissioners and service providers:

▯ Reduce waiting times and improve access to mental health services.

Actions: Healthwatch Oxfordshire to work with the Oxfordshire Clinical Commissioning group, CAMHS (Oxford Health NHS FT), TalkingSpace (Oxfordshire Mind and Oxford Health NHS FT), and GPs to tackle the long waiting times for accessing mental health services, including establishing ways of increasing efficiency of referral processes/systems.

For secondary schools, commissioners, and service providers:

▯ Provide more practical help and support for young people suffering from mental health problems/difficulties.

Actions: Schools and local mental health providers to ensure young people are provided with both spoken and printed material containing practical guidance on looking after mental wellbeing and information on how to go about gaining help when suffering a mental health problem. In addition, local commissioners to focus on providing more practical-based therapy options including CBT and Mindfulness, and to ensure that sufficient support is available to meet demand.

For mental health providers:

▢ Improve/consolidate the resources available for professionals for increased accessibility.

Actions: Increase awareness and accessibility of Oxfordshire Mind's: The Mind Guide to mental health services in Oxfordshire: a comprehensive guide to mental health services in the county. Oxford Mental Health Forum and Healthwatch to help promote the guide and work with increasing signposting of other resources aimed at professionals, including the newly launched MindEd e-learning portal supported by the Department of Health, via local providers including Oxford Health NHS FT and Oxfordshire County Council.

For secondary schools, GP services, and mental health providers:

▢ Ensure that there is sufficient support available for parents/carers.

Actions: Stakeholders and providers to help promote parent/carer groups such as the Oxfordshire Rethink Carers service, Oxford Health CAMHS parent group, and parent/carer support groups in schools, along with resources such as printed materials aimed at providing help and support to parents/carers. GPs to try and help identify if parents/carers need support themselves when seeking help for their child for mental health related problems.

Secondary schools

Key findings:

▢ Overall, schools feel that they do not have enough resources to be able to provide appropriate information and support to young people on mental health;

▢ The main barriers/difficulties identified were: not having enough resources to be able to provide the help and support needed; and a lack of training.

Recommendations:

▢ Organise more talks for students in schools from mental health providers, such as Oxford Health NHS FT, Oxfordshire Mind, or the Samaritans.

This was identified as a popular form of information and support that young people said they would have found helpful looking back to their first years at school. It was also identified as the top form of support that parents/carers felt their child would have benefitted from. Only three of the fifteen schools who took part in the survey said they provided this form of support.

▢ Provide more training on mental health to equip and support staff in schools: Identify training and resource gaps in schools and develop a programme of training to be delivered to address the gaps identified.

There have been recent reports in the national media calling for mental health to be included on the timetable in schools1. One of the key findings identified from this survey is the lack of resources and training available, which is fundamental in being able to facilitate improved integration of mental health information and support in schools.

▫ All schools should have counselling available.

Given the increasing levels of mental health issues reported, the increase in resources needed for schools, and that one-to-one support is the most popular form of support identified by young people as the type of support they would find most helpful; it is vital that all schools have access to counselling services available.

Young people

Key findings:

▫ 16% of the 324 young people who took part in the survey had not previously received or been given any information on mental health, or were unsure whether they had.

▫ Approximately half of those surveyed who had previously received information on mental health, found the information they received helpful (53%). The top sources were: online, school, mental health specialist, GPs. A greater percentage of males gained information online; a greater percentage of females than males gained information from their GP.

▫ 60% received all of the information that they needed (a slightly greater percentage of females than males).

▫ For those who had previously received help and support for a mental health problem, less than half (49%) found the information and support they received entirely helpful. The most common problems reported included the length of time for obtaining the help and support needed, and a lack of practical help and advice.

▫ When asked what forms of information and support young people would have found most helpful looking back to their first years at secondary school: One-to-one support with a professional was the most popular, followed by online material, a school visit from a mental health support group such as Oxfordshire Mind or the Samaritans, and printed material. A large proportion of respondents to this question, nearly half (46%), felt that they would not have found a mobile/tablet app helpful.

Recommendations:

The priorities for addressing young people's needs are:

▫ Reduce waiting times/increase ease of access to mental health services and ensure continuity of care.

▫ Provide more practical advice and support in helping to address mental health related problems.

▫ Focus on early intervention and increased mental health awareness and understanding, including offering wider support aimed at prevention and looking after mental wellbeing.

▫ Ensure sufficient mental health support is available both within and outside of school.

▫ Ensure there is a range of forms of information and support available for young people on mental health to address different needs, in particular, one-to-one support, online material, talks in schools and printed material.

Professionals

Key findings:

▫ The most common mental health problems/concerns encountered by professionals were young people who were feeling unhappy/depressed, worried/anxious, and problems related to self-harm or thoughts of self-harm (95% of professionals had encountered these problems). Young people who had been affected by bullying, feeling very stressed, feeling very angry, and relationship difficulties also ranked very highly.

▫ Over 75% of professionals who took part in the survey had encountered some form of difficulties or barriers in being able to provide mental health information or guidance and support needed to young people.

Recommendations:

▫ Reduce waiting times for referral for accessing mental health services, along with increasing ease of access.

The most common difficulties/barrier encountered by professionals was the difficulty in accessing other services if a referral was needed and a delay in being able to provide a referral if a referral to another service was needed (70% of respondents highlighted these two issues as the main difficulties/barriers).

▫ Improve the resources available, including increasing accessibility and availability.

Only 25% of the professionals surveyed felt that overall they had enough resources available to be able to provide appropriate information and support on mental health to young people. Several professionals suggested there should be more or improved material available on local services, mental health conditions, and information on medications.

Parents/carers

Key findings:

▫ 70% of parents/carers that took part in the survey specified that they currently had worries or concerns about their child's mental health. Only 33% felt able to give their child advice and support themselves, without additional help and support.

▫ From those who had been able to seek help, less than half found the information or guidance and support obtained helpful (40%). Over 90% had experienced difficulties in gaining access to the information or guidance and support needed.

Recommendations:

▫ Improve waiting times/ease of access to services.

The most common difficulty experienced by parents/carers in obtaining help and support for their child was the time it took to be able to gain access to the help and support.

▫ Ensure support is available to parents/carers themselves.

Several responses from parents/carers highlighted the wider impact mental health problems can cause, not least for the young sufferer, but the family as a whole, and the frustrations and difficulties parents/carers can experience when trying to obtain help and support.

Appendix 3 – recommendations arising from report compiled by My Life My Choice

With just over half those questioned being satisfied with the service provided by their GP's, there is room for improvement. User-led training in working with PWLD would be one way to ameliorate this situation.

▫ 68% of those questioned said that they have received an annual health check. This is a far higher figure than NHS statistics for 2012/13 (see page 36) and should be treated with caution. It is not known when respondents had their last health checks and many respondents have difficulty in differentiating between a health check & a regular GP visit.

Further and continuing MLMC involvement in partnerships with Health Care professionals, and much greater priority given to health checks by Health Care professionals would be highly desirable (see message from Health Champion page 36).

▫ The appointments system is fraught with difficulty. User-led training for administrative staff could help them improve on this & would potentially encourage PWLD to book appointments on their own behalf.

▫ Much work has taken place with regards to 'reasonable adjustments' and the Report found favourably in this respect. However, more could be done in respect of developing accessible (Easy Read) printed information and instructions for medication.

▫ On the whole there is some very good practice around PWLD feeling 'heard' by their GP's and the family carer/support worker being involved in the process. There is still some room for improvement around communication and inclusion of the person with the LD in these discussions. This, coupled with the fact that around half of our Group Members feeling that their GP's could know more about Learning Disabilities would also indicate that user-led training would be highly desirable.