

Brighton & Hove Big Health Service Check

2011:

A summary of feed back from local people with a learning disability and their carers

For the 2011 Big Health Service Check, specific services were focussed on based on locally identified priorities:

- GP practices including annual health checks & health action plans, and reasonable adjustments
- Hospitals including the learning disability liaison nurses
- Being healthy including healthy eating, physical activity and preparing/cooking food
- Support to be healthy (specifically for service users)
- Decision making and consent in health care (specifically for carers & staff)
- General questions about health services that people wanted to identify as providing a good service, or services that could be better at helping people with a learning disability

A questionnaire was developed to gather information and feed back from local services users, family carers and paid staff. The questionnaire asked the same of both service users and carers/staff, although there were questions about support to be healthy included in only the service user version, and questions about decision making & consent included in only the carer/staff version.

For the first time, questions were specifically included to gather demographic data, allowing the distinction to be made between feed back about the adult population (18 years plus) and those beginning transition (aged 14 – 17).

This questionnaire was circulated via a number of networks & contact lists, including the Community Learning Disability Team, local learning disability provider services, and via the Learning Disability Partnership Board contact list and web site. A prepared mail-out was provided to the Carers Centre and Amaze (two local organisations supporting parents & carers of people with a learning disability) for distribution to maximise the opportunity for carers to respond, as well as being distributed electronically.

In addition to this, both the Carers Centre and Amaze were encouraged to see feed back on the above listed services during focus groups, and were able to report their feed back at the Learning Disability Partnership Board meeting in July. Local service users were also able to discuss the topics at their Big Meeting – a regular meeting where service users from various local advocacy groups and learning disability services attend. Their feed back was also reported to the July Partnership Board meeting.

In total, **72** questionnaires were returned from local service users (all of whom were aged 18 or over), and **66** questionnaires were returned from carers & staff (10 regarding service users aged 14 – 17 years of age, and 56 regarding service users aged 18 years and over). This represents approximately **7%** of the known adult learning disability population, a decrease compared to the 13% that gave feed back for the 2010 Big Health Service Check. This decrease can be accounted for as a result of shortened timescales this year, which have not allowed for Getting Ready meetings or a Big Health Service Check Day to take place, as the number of service users returning a questionnaire by post remains similar (63 in 2010, and 72 in 2011).

Not every person who returned a questionnaire answered every question. Not every respondent included the names of the health services they use. Where percentages are given, they have been calculated according to the overall number of respondents, or the number of respondents for a specific question. In each section, outcomes are reported separately for the '>18 years' population, and for the '18+ years population'. Where available, a comparison with the 2010 data is given.

Main Themes

Theme 1: Population Data

Age of person completing questionnaire

- >18 years old population:

No service users aged 14 – 17 years returned a questionnaire. **100%** of carers that returned a questionnaire were aged 18 – 35 years.

- 18+ years old population:

36% of service users were aged 18 – 35; **43%** aged 36 – 60; **19%** aged 61 – 80; and **1%** aged 81+.

20% of carers were aged 18 – 35; **54%** aged 36 – 60; **14%** aged 61 – 80; and **4%** aged **81+**.

Age of population being supported

- >18 years old population:

Person supported is 14 – 17 years = **100%**

- 18+ years old population:

21% of people supported are aged 18 – 35; **43%** are aged 36 – 60; **5%** are aged 61 – 80; and for **30%** no age was given.

Post Code – area of residence

- >18 years population:

Carer postcode -

BN1 = **30%** BN2 = **30%** BN3 = **20%** BN41 = **0%**

- 18+ years population:

Service user postcode -

BN1 = **11%** BN2 = **13%** BN3 = **39%** BN41 = **1%**

Carer postcode -

BN1 = **21%** BN2 = **28%** BN3 = **25%** BN41 = **11%**

Ethnicity

- >18 years population:

90% of carers identified themselves as White, **10%** as 'Other'.

- 18+ years population:

96% of service users identified as White, **1%** as Black, **1%** as Asian, and **1%** as Mixed Race.

88% of carers identified as White, **5%** as Mixed Race and **4%** as Black.

Type of accommodation

- >18 years population –

Carers report **80%** of people being cared for live with their own family; **10%** in their own home; and **10%** in supported living.

- 18+ years population:

43% of service users report living in supported living; **29%** in a residential home; **10%** with their family; **10%** in a shared lives home, and **8%** in their own home.

41% of carers report the person being cared for lives with their family; **18%** in supported living; **18%** in a residential home; **11%** in their own home; **9%** in a shared lives home; and **2%** in 'other accommodation'.

Theme 2: GP practices

- >18 years population –

100% carers report that the person they care for has enough time at the GP surgery.

The questions regarding annual health checks and health action plans do not apply to anyone completing questionnaires about the >18 years population, as they are not eligible for annual health checks.

In terms of reasonable adjustments provided at the surgery, 12 responses were provided. **42%** of responses indicated they received no extra help at the practices, **17%** indicated they always see the same GP or nurse, **17%** indicated they did not need extra help, **8%** indicated they received longer appointments, **8%** indicated the practice used easy read information, and **8%** indicated another kind of help was given.

- 18+ years population –

83% of service users reported that they have enough time at the GP surgery (compared to 86% in 2010)

84% of carers/staff felt that the person they cared for had enough time at the GP surgery (compared to 94% in 2010)

72% of service users reported that they had received an annual health check and health action plan at their surgery (compared to 73% in 2010)

70% of carers/staff reported that the person they care for had received an annual health check and health action plan at their surgery (compared to 72% in 2010)

67% of service users reported receiving a copy of their health action plan from the GP surgery (compared to 38% in 2010)

41% of carers/staff reported that the person they support received a copy of their health action plan from the GP surgery (compared to 43% in 2010)

In terms of reasonable adjustments, a total of **92** responses were received from service users, and **59** from carers/staff.

For service users, **48%** responses indicated that they always saw the same GP/nurse, **18%** indicated they had longer appointments, **13%** indicated they did not need extra help, **11%** reported the practice uses easy read information, **8%** indicated no extra help was given, and **2%** indicated another kind of help was given.

For carers/staff, **31%** indicated the person they support always sees the same GP/Nurse, **29%** indicated the person always gets longer appointments, **29%** indicated the person did not receive any extra help, **5%** indicated the GP practice uses easy read information, **3%** indicated no extra help was needed, and **3%** indicated another kind of help was provided. Examples of the other kind of help given from both groups includes: easy access to nurses appointments; home visits; and providing a chaperone.

Theme 3: About the hospital

- **>18 years population –**

80% carers indicated that the person they support has been to the hospital in the last year

38% carers indicated that the hospital was good at helping people with a learning disability.

100% carers said they had not received support from the learning disability liaison nurses when they person they support had been to hospital in the previous year. This is to be expected, as the liaison nurses work in mostly adult services.

- **18+ years population –**

51% of service users indicated that they had been to hospital in the previous year (compared to 44% in 2010)

41% of carers/staff indicated that the person they support had been to hospital in the previous year (compared to 55% in 2010)

73% of service users indicated that the hospital was good at helping people with a learning disability (compared to 67% in 2010)

61% of carers/staff indicated that the hospital was good at helping people with a learning disability (compared to 77% in 2010)

35% of service users who had been to hospital in the previous year had received help from the learning disability liaison nurses (compared to 60% in 2010)

39% of carers/staff indicated help had been given by the learning disability liaison nurses (compared to 32% in 2010)

85% of service users indicated that the learning disability liaison nurses were good at helping people with a learning disability (compared to 93% in 2010)

78% of carers/staff indicated that the learning disability liaison nurses were good at helping people with a learning disability (compared to 86% in 2010)

Theme 4: Being Healthy

- >18 years population

3 responses were given to the question about health information provided by the GP practice –

33% indicated healthy weight information had been given, **33%** indicated being active information had been given, and **33%** indication other information had been given. This was identified as counselling information.

Healthy eating –

70% of carers said they person they support receives a lot of support to choose healthy food, **20%** indicated the person received some support, and **10%** indicated the person received no support.

Of the **70%** that receive a lot of support, **57%** was identified as wanting help, and **29%** were identified as not wanting help.

Of the **20%** who receive some support, **50%** were identified as wanting help, and **50%** as not knowing if they wanted help.

Of the **10%** that receive no help, **100%** were identified as wanting help.

Being active –

60% carers said the person they support receives a lot of support to be active, **20%** indicated they receive some support and **20%** indicated they receive no support.

Of the **60%** that receive a lot of support, **83%** want help, and **17%** don't know.

Of the **20%** who receive some support, **50%** want help and **50%** do not want help.

Of the **20%** who receive no support, **100%** want help.

Cooking meals –

50% of carers said the person they support receives a lot of support to cook meals, **20%** indicated they receive some support, and **30%** indicate they receive no support.

Of the **50%** who receive a lot of support, **80%** want help and **20%** do not want help.

Of the **20%** who receive some help, **50%** want help and **50%** do not want help.

Of the **30%** who receive no help, **33%** want help, **33%** do not want help and **33%** do not know.

Asking for help/training -

60% of carers indicated they knew who to ask for help if they required training/support with these areas, and **40%** indicated they did not.

- 18+ years population

Who helps you to be healthy? –

165 responses from services users were received for this question. **36%** indicated their support worker at home helps them, **19%** indicated the GP/practice nurse helps them, **18%** indicated their family help them, **13%** indicate their support worker at their day centre helps, **7%** indicate others help them, **5%** indicate their friends help them, and **1%** indicated an advocate helps them.

Examples of the other helpers include: 'CLDT', 'carer', 'myself' and 'gym'.

97 responses from service users and **77** responses from carers/staff were given to the question about health information being provided by the GP practice.

For service users, **33%** indicated they had received information on healthy eating, **24%** received information on healthy weight, **20%** received being active information, **19%** received other information, and **5%** received information on cooking food.

For carers/staff, **32%** indicated they had received information on healthy weight, **29%** received information on healthy eating, **24%** received information on being active, **13%** received other information, and **3%** received information on cooking food.

Examples of the other information include: stop smoking; alcohol use; oral health; and skin care.

Healthy eating –

61% of service users indicated they receive a lot of help to choose healthy food, **28%** receive some help, and **4%** receive no help.

Of the **61%** who indicated they receive a lot of help, **68%** want help, and **20%** do not want help.

Of the **28%** who indicated they receive some help, **50%** want help, and **40%** do not want help.

Of the **4%** who receive no help, **33%** want help and **66%** do not want help.

64% of carers indicated that the person they support receives a lot of help to choose healthy food, **13%** receive some help and **7%** receive no help.

Of the **64%** who indicated the person receives a lot of help, **72%** want help and **19%** do not want help.

In addition to this, 4 people were identified as being PEG fed.

Being active –

43% of service users indicated they receive a lot of help to be active, **44%** report receiving some help and **6%** report receiving no help.

Of the **43%** that receive a lot of help, **61%** report wanting help, and **29%** do not want help.

Of the **44%** that receive some help, **44%** want help and **41%** do not want help.

Of the **6%** that receive no help, **25%** want help and **75%** do not want help.

46% of carers/staff indicated that the person they support receives a lot of help to be active, **35%** receive some help, and **11%** receive no help.

Of the **46%** who receive a lot of help, **69%** want help, and **19%** do not want help.

Of the **35%** who receive some help, **65%** want help and **25%** do not want help.

Of the **11%** who receive no help, **50%** do not want help and **0%** wants help.

Cooking meals –

49% of service users indicate that they receive a lot of help to cook meals, **26%** receive some help, and **17%** receive no help.

Of the **49%** who receive a lot of help, **91%** want help, and **6%** do not want help.

Of the **26%** who receive some help, **58%** want help and **26%** do not want help.

Of the **17%** who receive no help, **17%** want help, and **83%** do not want help.

36% of carers/staff indicated that the person they support receives a lot of help to cook meals, **23%** receive some help, and **18%** receive no help.

Of the **36%** that receive a lot of help, **50%** want help and **25%** do not want help.

Of the **23%** that receive some help, **69%** want help and **31%** do not want help.

Of the **18%** that receive no help, **50%** want help and **50%** do not want help.

Asking for help/training –

90% of service users indicated they knew who to ask for help with these areas, with many indicating they would ask support/key workers.

52% of carers/staff indicated that they knew who to ask for help/training in these areas, and **30%** did not know who to ask.

It is interesting to note that service users appear to rely on those caring for them to know where to find help & support, yet only 52% of staff/carers indicate that they would know who to ask. This would suggest that targeting awareness and education at carers & staff would be effective, and supports the training strategies planned locally around health & health promotion training.

Theme 5: General Questions

These questions apply only to carers/staff and are about involvement in decision making, and giving consent.

- **>18 years population –**

60% of carers indicated they had been involved in making decisions about the health care of the person they support.

70% of carers indicated they have been asked to agree to medical treatment on behalf of the person they support. This is not surprising as they are caring for under 18's and in these cases are likely to be giving parental consent.

- **18+ years population –**

78% of carers/staff indicated they had been involved in making decisions about the health care of the person they support (compared to 86% in 2010)

46% of carers/staff indicated they had been asked to agree to medical treatment on behalf of the person they care for (compared to 30% in 2010). **41%** of carers/staff said they had not been asked to give consent on behalf of the person they care for (compared to 65% in 2010).

According to the Mental Capacity Act, no-one should be asked to give consent on behalf of another adult.

Theme 6: commenting on local health services

In response to the question, 'which health services are good at helping people with a learning disability', the most common responses were:

- **>18 years population –**

Seaside View (x 3)

Royal Alexandra Hospital (x 2)

Dentist (x 2)

CAMHS (x 1)

Amaze (x 1)

- **18+ years population –**

GP (x 49)

Dentist (x 31)

CLDT (x 20)
Nurses (x 15)
Hospital (x 11)

(Services were grouped together in categories for the purpose of reporting here)

In response to the question, 'which health services could be better at helping people with a learning disability', the most common responses were:

- >18 years population –
Hospitals (x 5)
All services (x 1)

- 18+ years population –
GP (x 15)
Hospitals (x 9)
Mental health (x 7)
Dentist (x 4)

(Services were grouped together in categories for the purpose of reporting here)

The final question allowed respondents to make any additional comments they wished about local health services. The responses were categorised into positive, negative and mixed:

>18 years population: **60%** of the comments were classed as negative, and **40%** as positive.

18+ years population: **52%** of the comments were classed as negative; **36%** as positive; and **12%** as mixed.

The outcomes of this questionnaire and resulting report will be used to support both current and new projects that aim to address local health inequalities and identified need.

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