

**OUR 'BIG PLAN' FOR SUPPORTING
ADULT RESIDENTS WITH A LEARNING DISABILITY IN
WESTMINSTER AND KENSINGTON AND CHELSEA,
2018-2021**

**Report of the Launch Event, held on
20th November 2018, at
Kensington Town Hall**

Introduction

The City of Westminster and the Royal Borough of Kensington and Chelsea, Central London Clinical Commissioning Group (CCG) and West London CCG commission a range of services to support residents with learning disabilities to live full, safe and healthy lives. The Councils act as lead commissioner for these services, working with the CCGs, to make the best use of joint investment.

On Tuesday 20th November 2018, the Bi-Borough Integrated Commissioning Department of the City of Westminster and the Royal Borough of Kensington and Chelsea launched the Councils' and CCGs' Joint *Big Plan for supporting adult residents with a learning disability, 2018-2021*. This was co-produced over a period of six months by Local Authority and Clinical Commissioning Group commissioners, the community Learning Disability teams, resident adults with learning disabilities, their parent / family carers, providers and other key stakeholders.

There were 85 attendees at the Launch Event, which included Councillor Sarah Addenbrooke, Councillor Iain Bott, 6 service users, 15 parent carers and team members from in-house day centres and employability services in RBKC and WCC.

The Launch

The event began (agenda attached as appendix one) with a welcome from Anna Waterman, Strategic Commissioner, who led the development of the *Big Plan* and who noted that its production was thanks to the commitment of the many stakeholders and that the *Big Plan* can now act as a tool to ensure that commissioners deliver on the commitments made.

Ms Waterman introduced Councillor Sarah Addenbrooke, Lead Member for Adult Social Care for the Royal Borough of Kensington and Chelsea and Councillor Iain Bott, Deputy Cabinet Member for Family and Health Services for the City of Westminster. The Councillors noted that the *Big Plan* offers the vision for how existing good work will be sustained and built upon, highlighting areas for improvement and how this improvement will be delivered. They thanked those that had been part of its production, asserting how important co-production, the genuine involvement of residents in particular, is to ensuring that the Big Plan signals meaningful development.

The *Big Plan* itself was then presented to delegates by adult residents with learning disabilities, elected by their peers to represent their interests in the design and delivery of services and supported by The Advocacy Project. Their presentation is attached as appendix two.

Sue Redman from *Full of Life* and Hend Rahman from *Westminster Parent Participation Group* then presented a carer's perspective on how delivery of the *Big Plan* will make a meaningful difference to the lives of families of people with learning

disabilities and why is so important that carers' roles in the circle of support are kept in focus. They stressed the importance of planning support for adulthood early.

The second half of the event gave delegates an opportunity to discuss the delivery plan, section four of the *Big Plan*. While some elements of the delivery plan were already well developed at the time of the launch, others needed a bit more flesh on the bones and delegates were able to choose between four 'workshops' to progress this. Delegates were specifically asked to weave into workshop discussions any particular concerns or considerations pertaining to young in transition to adult services from children's services. Finally, delegates were also invited to flag any glaring omissions in the delivery plan.

The four workshop centres around the following four priorities:

1. Getting and staying healthy
2. Making my home my own
3. Being part of the community
4. Good support for parent and family carers

The issues discussed are outlined below.

Getting and staying healthy

Attendees of this workshop considered reasonable adjustments as needing to be improved for people with learning disabilities, in particular ensuring staff are trained appropriately. They suggested the development of a 'fast track' for the service users as a way of addressing the issues caused by extended waiting times for appointments.

There was mixed feedback regarding the quality of care and the group asserted the need for services to ensure that all services offer a good standard of care. Particular issues were raised regarding care pathways needing to be smoother and regarding follow-on care.

The importance of planning in delivering effective and efficient services was discussed, emphasising the importance of moving from a focus upon reacting to crises to a service focused on prevention and planning. In particular, access to health checks and the development and implementation of effective health action plans were raised as important, as was having a strategic focus anticipating necessary services e.g. flu jabs.

Communication was a key theme throughout the discussion and this is clearly important for people with learning disabilities, especially where they are autistic. The group suggested all sections of the pathway need improvement and ideas to do so were suggested. Importantly, the appointments with health practitioners need to allow for adequate time for discussion and understanding to take place between the

practitioner and patient, with 'easy read' information and no jargon being used, including in regards to medication. Specifically for GP surgeries, attendees pushed for having a 'Learning Disability Champion' in each practice as a standard, and the group also deliberated having a specialist 'mobile GP'.

To streamline services, the utilisation of health plans/passports (in easy read) was emphasised, ensuring these record long term conditions like diabetes and that hospitals make use of the health plan/passport during visits. The group raised that it needs to be clarified as to who is responsible for completing and updating these.

Finally, the importance of reducing the amount of health and social professionals involved in service delivery was discussed. Also the benefit of having direct contact with the clinician in community and secondary care – ultimately reducing the number of steps in the service processes.

Places to Live

In the workshop focused on 'Places to Live', five themes emerged:

- Planning early
- Information sharing
- Independent living
- Physical aspects of the housing
- Staffing.

Planning early should happen with parent carers, who need an adequate amount of time to make necessary modifications to their home. Service users also need to start learning about their new area/local amenities where they are going to be living near in good time before they move their new home to ensure they are familiar and comfortable - travel training is an important aspect of this to be completed before they need to travel independently. These aspects are underpinned by adequate funding to provide a quality service, as well as good planning for when things go wrong, as well as for when they go as desired.

Information sharing, including trust and strong communication, has a vital effect upon the smooth running of services and hence allows for effective communication of the options available. Attendees discussed how services were organised in the past: there used to be a 'housing liaison officer', who liaised with stakeholders and had a positive impact on efficiency. The group suggested that conversations should occur with housing associations about shared housing for respite/long term. As well as this, the group emphasised the occurrence of regular discussions about housing options with parent carers, with representatives from the following to be invited: housing allocations; investment team; housing associations and planning.

In terms of Independent Living, the development of community housing was encouraged as a way to provide for those who live on their own, including those with

complex needs. It was highlighted how it has been difficult in the past to find a provider who is able to offer specialist support, particularly where service users have complex needs. *Full of Life* are interested in exploring community housing, a potential site existing at Carlton Gate. It was emphasised how independence doesn't work for everyone e.g. some service users benefit from a communal area, so people can mix. Without this it can create a false economy and effect quality of life, such as by aggravating social isolation.

Alongside this, the physical aspects of the housing need to be suitable for the particular needs of the residents e.g. big enough. The home needs to provide a safe space for users, and the services must work closely with families to understand individual needs, with a flexible and personalised approach for each individual. As discussed earlier, service users need to be familiar with the area they live in, and where possible local options should be available so service users can stay in-borough, but where this isn't, service users need to be introduced to the area and amenities in good time before moving to the area. Importantly, the group recognised that 'home' doesn't only refer to the physical building, achieving the right mix of people who live in shared living conditions is equally important.

Continuing this theme, staffing was the final focus of this workshop. The group discussed how vital it is for staff to be kind, compassionate, adequately skilled/qualified (specific to each service-user's needs) and, most importantly, that they have the right attitude and values, as these cannot be taught. The latter attribute can be a focus during the carer recruitment process, which can be assessed by running specific workshops in the recruitment process. The group discussed the importance of retention and consistency of staff as extremely important, as it ensures the maintenance of rapport and knowledge. Retention is an issue in the sector for reasons such as low pay. As well as this, the standard 12-hour shifts may put off individuals with other responsibilities from applying for a job as a carer e.g. family carers sometimes want jobs in care. The group discussed the importance of motivating caring staff in others ways. Staff should also be encouraged and recognised via verbal appreciation, to demonstrate how they are individually appreciated.

Being Part of the Community

In this workshop, delegates discussed how people can be helped to access/engage in their communities. Throughout all aspects of being within the community it is important that adults with learning disabilities have their support built around each individual, as well as always having access to a safe space which is clearly signed, with trained/aware staff, space for safety in crisis, cards for identification, and it was suggested that the services could use the two Apps that have already been created (or similar), which help to develop skills. The importance of considering the full set of activities required to deliver a service a built into the funding model – not just contact time.

The need to secure improved familiarity with existing community assets was highlighted, including whether they are appropriate / can be adjusted for the use of people with learning disabilities including ensuring easy-read information is provided.

Other aspects that need to be specifically considered throughout community services are ensuring service user inclusion in procurements, the continuous theme of travel training to foster independence (which needs to be of high quality and there is the option of using TFL's current services), and the continuous work with services and businesses to ensure awareness and adaptability to the needs of people with learning disabilities. Within this, there is great importance of working with the police/community officers (and the general public), on the issue of hate crime towards people with learning disabilities, which could be done by using social stories to help people understand individuals. Training for organisations ensures the visibility of service users, as it becomes the norm, which means service users can feel safe and their confidence is then improved.

The group discussed a range of specific community-inclusion activities and how these can be adapted for adults with learning disabilities. Employment services could be adapted by using pre-recorded video as part of interview process for those who need communication/confidence support. Supported internships should be utilised, especially as 50%-60% of interns progress to employment. Employment also needs to be paid and sustainable, with businesses and employers taking part in specialised training to make sure they know how best to support their learning-disabled employers. Other activities, including volunteering, can be provide with a 'try before you buy' route. Alongside this, the group emphasised the importance of the service users taking part in lifelong learning and education, with a specific mention to the importance of multi-media support/ICT skills. Strong transition pathways support the prospect of learning-disabled adults, which means SEND pathways need to be utilised, as does the use of mapping post-16 years' needs and raising awareness about employment before individuals leave school.

Support for family carers

In the workshop the group discussed various ways to improve the current support provided for family carers. As part of this, carers emphasised the need for quality front line services they can trust for the person they care for. They stressed that they do not feel able to use carer services unless they are confident that the person they care for is happy and safe.

Concerns were expressed about the level of specialised knowledge in services, the staff turnover, reliability and the level of compassion shown to service users. It was noted that poor pay within the industry perpetuates the challenges.

Other issues carers raised included:

- the difficulties and lack of understanding of direct payments

- the challenges associated with navigating systems relating to carers' entitlements and advocacy
- the challenges associated with transition from children's to adults' social care
- services available when more intensive support is required in times of crisis.

The group emphasised the importance of ensuring parents were acknowledged and respected as carers, and that there was adequate amount of support for siblings of disabled children.

Next steps

Anna Waterman closed the event, reiterating that the discussion held during the Launch would inform the delivery of the *Big Plan*. All were thanked for their invaluable contribution both to the development of the *Big Plan* and the launch workshops.

Evaluation

An evaluation questionnaire was completed at the end of the event, and 25 were completed (29%). 100% of respondents agreed that the event had helped them to understand how the Big Plan will make an impact, and respondents positively commented on the 'openness' and collaborative-feel of the event. There was a request from some delegates for further events of this type to encourage collaborative partnership working relationships and problem solving. A more detailed outline of the findings can be found as appendix three.

Appendix one: Agenda

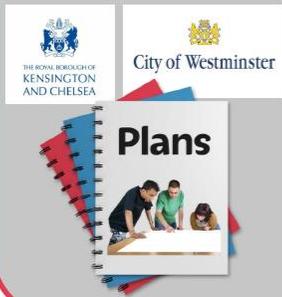
How the meeting will work

	Tea or Coffee	 9:30
	Welcome from Anna Waterman, Strategic Commissioner	 10:00
	Introduction to the Big Plan Councillor Iain Bott of Westminster and Councillor Sarah Addenbrooke, of Kensington and Chelsea	 10:10
	Our Say about the Big Plan 2018-2021 Residents' Forum Representatives	 10:20
	Our say about the Big Plan, Family Carers	 10:40
	Tea or Coffee	 11:00
	Delivering the Big Plan Introduction to Workshops – Anna Waterman 1. Getting and staying healthy 2. Places to Live 3. Being Part of the Community 4. Support for family carers	 11:20
	Lunch	 12:30

Appendix two: Presentation of the *Big Plan* by adults with learning disabilities

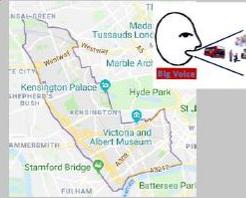


your voice your rights your choice



The Big Plan: Bi-Borough Support for Adults with a Learning Disability

2018 to 2021



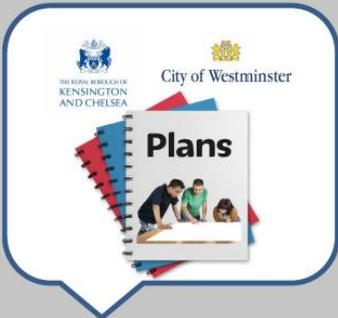
We are the Bi-borough
Learning Disability
Partnership Board Reps



People with learning
disabilities elected us
so that we could speak
up and have our say.



We work in partnership
with Council and Health
officers to make sure
people with learning
disabilities are listened
to and are included in
planning services.



We would like to tell you about all the ideas in the **Big Plan**.



What needs to get better?



- Planning Together (Co-production)



- Getting healthy, staying healthy



- Making my home my own



- Being part of the community
- Support to become an independent adult
- Good support for parents and family carers



Planning Together (Co-production)

9



- Being clear about what Co-production means
- Talk about changes that can make things better

10



- Tell us what you do with our feedback
- Include people with higher needs in planning their support

11



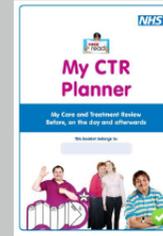
**Getting healthy,
staying healthy**

12



- Healthcare should be easier to use
- Doctors and nurses need to make sure we understand what they tell us

13



- Access to mental health services when we need them
- Making sure annual health checks happen for all
- Health Action Plans need to be made and used

14



Making my home my own

15



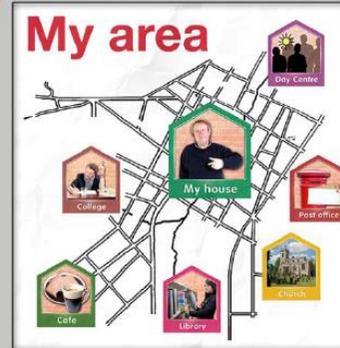
- Choosing where I live
- Support to understand my choices

16



- The neighbourhood needs to feel safe and secure
- Support to understand my tenancy agreement

17



Being part of the community

18



- Include us, make your services accessible
- Support our independence. We need safe places in the community where we can go if we are worried or scared



19



- We need support to make the most of our evenings and weekends



- We want support with our relationships – friendships, sexual health and coping with death

20



Support to become an independent adult

21



- Help young people to understand their choices before they move into adult services



- Support young people so they learn the skills they need to be independent

22



- Support young people to think about jobs they would like to do in the future



- Young people need support to have a social life as they become adults

23



Good support for parents and family carers

24



- Parents and family carers need help with caring for others
- They need support with their own health and wellbeing



25



- Help parents and carers to support us in making choices about who gives us support
- Having breaks helps us and our families. We need more choice with the type of breaks that we can take
- Sometimes, we need support quickly. This needs to be available. It helps us and our families.



26



Making things better

27



- Support should be person centred
- Support should help people to be independent
- Health and Social Care need to work together better

28



- Safeguarding should be important to everyone
- All support should be the best
- Better choice of support

thank you



Thank you for listening to us

Appendix three: Findings of the evaluation

Survey response rate: 29% (25 respondents)

1. Has this event helped you to understand how the Big Plan will make an impact?

Yes - 25

No - 0

2. To what extent did the presentations in the first half of the event provide an overview of the Big Plan and the different needs of stakeholders?

(1: Not at all; 6: Very Well)

Response	Frequency	Percentage
1	0	0%
2	0	0%
3	2	8%
4	2	8%
5	8	32%
6	11	44%
I couldn't attend this session / Did not respond	2	8%

3. Which workshop did you attend?

	Frequency	Percentage
Getting and staying healthy	6	24%
Places to live	8	32%
Being Part of the Community	6	24%
Support for family carers	4	16%

4. How do you rate the usefulness of the workshop you attended?

(1: Very poor; 6: Very good)

OVERALL

Response	Frequency	Percentage
1	0	0%
2	0	0%
3	2	8%
4	0	0%
5	9	36%
6	13	52%
I couldn't attend this session/ Did not respond	1	4%

Getting and staying healthy

Response	Frequency	Percentage
1		0%
2		0%
3		0%
4		0%
5	1	17%
6	5	83%

Places to live

Response	Frequency	Percentage
1		0%
2		0%
3		0%
4		0%
5	4	50%
6	4	50%

Being Part of the Community

Response	Frequency	Percentage
1		0%
2		0%
3	1	25%
4		0%
5	2	50%
6	1	25%

Support for family carers

Response	Frequency	Percentage
1		0%
2		0%
3	1	25%
4		0%
5	2	50%
6	1	25%

5. Describe what worked well:

- Everything it was amazing
- Housing and everything
- Hearing the voices of people with LD
- Facilitation; service users and family/carer involvement opportunity to engage in the discussion
- Openness; understanding the needs of people with LD
- Everything was good thank you for everything you have done. May God bless you! And make success of your plan.
- Working together with providers and carers
- Good listening was there hopefully will put into action what said
- Hearing from service users and carers
- Communication

- Listening other experiences, Q+A, (passing) advice, parents rep presentation, customer presentation
- The experience and the contribution from all parties
- The presentation of advocates/ reps and carers
- Feeling like we were listened to
- To knowledge what sort of service carers we would like to
- The carers talk
- Workshop was good

6. Describe what did not work well or requires improvement:

- Rooms for workshops - noisy
- There was no enough seats for late comers
- Carers service needs better training and understanding. Social service also to be alert with better understanding and make it happen
- Communication, listening in all areas
- Location
- Drinks, more chair and tables
- Need to happen more often
- Not attending every workshop because they all need to everyone
- Some people talked more than other

7. How did you find the pace of the event?

(1: Very poor; 6: Very good)

Response	Frequency	Percentage
1	0	0%
2	0	0%
3	1	5%
4	5	23%
5	8	36%
6	8	36%

8. Do you have any comments regarding the venue for the launch event?

- Nice
- Venue was good and we got some positive knowledge
- Very good
- Could be better and comfy
- Not big enough to accommodate
- Too small
- More rooms for work-shops
- V.good
- Thank you!
- Very good
- To make more
- It should be bigger

9. Do you have any comments regarding the refreshments for the launch event?
- Hope lunch will be good
 - good
 - Thank you!
 - Biscuits would be nice
 - Needed more tea/coffee
 - The customer we support could make a better hot drinks if paid. It's a good idea for future events
 - Could be better
 - Good tea
 - Coffee is poor!

10. Overall, how did you find the launch event?
(1: Very poor; 6: Very good)

Response	Frequency	Percentage
1	0	0%
2	0	0%
3	1	5%
4	3	14%
5	8	38%
6	9	43%