

Response to Big Plan from Oxfordshire Family Support Network

Draft Big Plan 2015-2018 Strategy

Firstly, we want to thank OCC for the efforts that staff have gone to give people with learning disabilities, their families and other organisations the opportunity to comment on this document by providing additional meetings around the county and by their willingness to meet with us to debate the ideas and vision contained within this document.

Part 1: The Vision

The vision and strategic priorities set out in page 4 and 5 are sound and build on the vision contained in the Valuing People White Paper 2001 and Valuing People Now 2009. We also welcome a vision that affirms the right for people with learning disabilities to play an active part in their communities as equal citizens, to have choice and control and to lead healthy, successful, independent and safe lives, with good timely access to health and social care services.

However, the strategy presented in this document presents a number of proposals that are radical and revolutionary, rather than evolutionary in their approach so we are cautious about the possible adverse impact of this strategy on the lives of people with learning disabilities.

Part 2-The Priorities

We agree with the four overall priorities, though we have real concerns about how far it is possible to achieve these given the financial savings that have to be achieved. These are additional savings to those already made over the last four years. This strategy seeks to transform both specialist and mainstream services but we feel that this will be difficult to achieve without additional transitional funding.

We think that Priority 4 should be the top priority as mentioned in your document, as good health and wellbeing and safety, is essential to achieve the other priorities.

Priority 1

"We will enable people with learning disabilities to have more choice and control over their lives"

We do agree with this priority, though the level of reduction in spending on an increasing population of people with learning disabilities makes this challenging. Providing person-centred support through personal budgets has the potential to create and unlock resources for people with learning disabilities.

Market Shaping and Commissioning

There is a great deal to be done to create a more flexible market so the people can make best use of the budget that is allocated to them. If people have funding but nowhere to purchase the services from, this creates a problem not a service.

This is particularly the case where people have complex health needs, or mental health needs and challenging behaviours. Choice and control could so easily become hollow and meaningless in those circumstances without the right support to develop these choices.

Support to use personal budgets

We also recognise that many people do not want to take on the challenges of managing a direct payment themselves. It is vital that local advice and support gives people choice in managing their personal budgets. The document has nothing to say about the role of user-led organisations or about whether independent brokers will be part of this strategy.

Use of Mental Capacity Act

We also hope that Social and Health Care services will offer training to staff to ensure that the Mental Capacity Act is used in a supportive way for people with learning disabilities and that "choice and control" is not used to prevent families being able to be involved in supporting decision-making where it is the wish of the person they support.

Priority 2

"We will enable people with learning disabilities to take an active part in their communities, through work, volunteering, friendships and other opportunities."

We strongly support this priority, to enable people with learning disabilities to lead fulfilling lives.

Co-creation and Co-production

We would wish to see both people with learning disabilities and their families contributing to the co-creation and co-production of services and support as experts by experience. As families, we celebrate the skills and abilities our relatives have and want to be ambitious for their future lives.

We strongly believe that harnessing the skills and potential of people with learning disabilities and their families, working in partnership with communities, the voluntary sector and the statutory sector enhances the lives of all concerned. The work of organisations such as The Foundation of People with Learning Disabilities Community Connecting project would be able to provide valuable training and a business model.

Priority 3

"We will enable people with learning disabilities to make choices about where they want to live, and support them and their families with their decision"

We agree with this priority but feel that given the cost of housing in Oxfordshire, this is very challenging. Nationally, the evidence points to the fact that the vast majority of adults with learning disabilities will be living with their families and that this is the also the case in Oxfordshire.

Links to Housing Strategy

The strategy refers to people having choice about where they live. How will this strategy link with the housing strategies of the District Councils in Oxfordshire?

Could OCC work with the District Councils, Housing Associations and families to explore how housing stock can be increased? Will there be any plans to make it easier to transfer tenancies to people with learning disabilities who live in social housing when their parents die?

Has there been any exploration of how private landlords could be encouraged to support more people with LD e.g., through the Golden Lane Good Tenants scheme or a local equivalent whereby people with LD are supported to manage private tenancies?

The Government's decision to cease the Support to Mortgage Interest (SMI) has meant that the shared home ownership market where families could assist with the purchase of the property has been effectively eliminated as a housing option.

We agree with the suggestion that extra-care homes specifically for people with a learning disability on a small scale or core and cluster housing could be a good approach to improving housing options in the county.

Information and Advice

The document refers to universal information and advice services in response to the Care Act taking into account the needs of people with learning disabilities, their families and carers.

If people are to make best use of personal budgets, they need **independent information** that is accurate and has not just a breadth but a depth of knowledge about LD. OxFSN was set up because many families who have relatives with LD did not find the information provided by universal services relevant or sufficiently knowledgeable.

Strategic Intentions

The strategic intentions to have access to all the services that everyone else is on initial examination a worthy aspiration.

However, we are very concerned that there are still significant inequalities in access to mainstream health services particularly. We do not feel that the Service and Community Impact Statement addresses the consequences if we get this wrong.

Case Study 1

A young lady with profound and complex learning and health problems recently attended an annual epilepsy clinic at the JR (she has complex and intractable seizures). The view of the consultant was that they should consider raising the level of Epilim which is one of three anticonvulsants she takes. He was proposing to write to Tim Andrews (Consultant Psychiatrist with the Learning Disability Team) as he knows the young lady well, to ask his advice and that of her GP.

Under the new way of working, who would he consult with? Who would oversee this change and who would be responsible for future preventative action as described in the Care Act? If she had to wait for a further appointment, this could be hugely detrimental to her health and wellbeing and in fact be very unsafe.

Case study 2

A young person with profound and complex disabilities has recently not passed urine for more than 36 hours. Naturally everybody was extremely concerned. The person was taken to the GP who was reluctant to catheterise. Fortunately the problem resolved itself but there was a view that because of the severe learning disability the person may have been unwilling to pass urine. What would happen in these circumstances? How would reasonable adjustments help? What power would they have and would there be sufficient number in the team to meet the needs of such people?

The Confidential Inquiry into the Premature Deaths of People with Learning Disabilities found that:

*The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. **Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.***

37% of deaths were avoidable.

The expectation of living a productive life, with minimal dependence on services.

Our comment is that clearly out of the 11,000 people identified with LD, the vast majority are doing just that with their lives already. The challenge is to ensure that the approx. 2,000 people with substantial or critical needs who are receiving a paid service can be enabled to lead a productive life with minimal dependence on services. We do recognise that linking people with those who are not paid to be in their lives is really valuable and builds inclusive communities but there will be people who will always need significant support to live their lives fully.

Commissioning Intentions

Reasonable adjustments team

It is not clear to us from this document whether the reasonable adjustments team will be operating at **strategic level** or at **operational level** with individual people with learning disabilities. We feel that this team would only make an impact if the team is empowered to insist that adjustments are made to mainstream health and social care services. The team working within all the local hospitals needs to be expanded to build on the excellent work of the Hospital Liaison Nurse.

"Mainstream staff must have good training in disabilities so they know what they cannot provide themselves and be ready to contact the reasonable adjustments staff. A bit like GPs who then refer on to consultants. What we don't want are only GPs."

However, there needs to be a comparable role within the CCG, to ensure that changes take place. The greatest challenge of all is to impact on the GP surgeries as they are autonomous businesses contracted to the CCG. It may require someone with a role reporting into the Board of the OCCG, to ensure that the mainstreaming is kept on track and that it should be a GP who takes this role on as it is likely to have greater impact.

Need for incentivised practice

A recent report in the National Elf Service blog explores the need for incentivised GP practices to support people with Down Syndrome. They suggest that the average GP practice has 2.82 adults with Down Syndrome in the average practice population.(1) Source and full article at <http://bit.ly/1JYyNUk> Their findings indicate that amongst incentivised GP practices the rate of newly identified health conditions was higher.

We know that there are still considerable challenges to ensure that all GP services in Oxfordshire provide good health care to people with learning disabilities. Some are excellent but others still need to improve to ensure that people with learning disabilities receive **comparable** care to non-disabled adults. **We do not yet have a level playing field. Some of the issues lie in diagnosis of co-morbidities that occur as a result of specific and sometimes rare conditions, as well as issues around insufficient skills in communication with people with learning disabilities.**

There have been many national campaigns highlighting the tragic consequences of poor health care for people with learning disabilities, such as Death by Indifference (Mencap 2007) and Death by Indifference: 74 Deaths and Counting (Mencap 2012)

We simply cannot afford to ignore these findings if we wish to provide safe care for people with learning disabilities in Oxfordshire.

Specialist GP consultant role

In the Netherlands, there are specialist GP consultants who work in primary care to provide support to GPs colleagues and to run specialist GP services for those with the most complex needs. We are not clear from the description of the reasonable adjustments team if there would be any clinical input from GPs or learning disability mental health specialists.

Dental Service access

We also know from many families that we have spoken to, that access to dental services for people with LD is still very problematic. Those who have used services such as the one in Manzil Way have spoken highly of the support they receive but the experiences of mainstream dental services have been less good. If general anaesthesia is required, there can be a long wait for services.

Case study 3

A young man aged 24 with severe/profound learning disabilities and no verbal communication was exhibiting behaviour which pointed to a problem with his teeth. His staff team took him to visit the mainstream dental service on several occasions to check whether he needed treatment. They were unable to ascertain this, because of the difficulties with getting him to open his mouth. It was felt by his Mother (and agreed by the staff) that he would need to be sedated to get a proper look inside his mouth. (This used to happen when he was in children's services). This took several months to arrange by which time he needed two teeth removing and one filling.

We cannot emphasise enough that these health inequalities are real and are experienced every day by people with LD and their families. We are therefore very concerned about the speed at which this strategy is moving towards mainstreaming health care. It is not clear if additional resources will be made available to do this.

We do not wish to see an increase in mortality and morbidity in the population of people with LD in Oxfordshire. This requires very careful monitoring by local HealthWatch and by OCC and OCCG.

Mental Health Services

We also have concerns about the impact on local mental health services and on the lives of people with learning disabilities who have mental health needs if careful thought and preparation is not given to the support and resources required.

We remain committed to a vision of an intensive support service that provides local, accountable small –scale provision of mental health services to those with the highest levels of need. We also recognise that for a few people, the only solution that will work is a bespoke service, tailored to individual need.

Case study 4

J (aged 16) with very high levels of need is effectively bed blocking mainstream CAMHS services at the Highfield Unit, as there is nowhere to move him on to locally and his level of distress is so high that others cannot be placed in the same ward with him.

We welcome the awareness that services have to radically change to deliver care safely and locally for people with learning disabilities. The failures of Southern Health to deliver effective and safe local care are well documented but we need professionals of high calibre with the specialist knowledge of mental health needs and behaviours that challenge in order to provide services close to home for both young people and adults.

We recommend that a formal partnership is set up between the mainstream mental health services run by Oxford Health and a trust with experience of running LD mental health services such as the Berkshire NHS trust.

Nationally, mental health services have had funding reduced by 32% during a time when acute services have had a tiny positive growth.(0.9%).We fear that mainstream services which are already weak will be put under pressure if we do not offer appropriate support that genuinely meet the needs of people with learning disabilities. Everyone will be failed if this is not addressed.

Families have particular fears about the safety of vulnerable people with LD on mainstream wards, particularly around the risk of financial and sexual abuse.

Equally, we need to acknowledge that some people with LD pose a real risk to themselves or to other members of the community so a no beds option will not be safe or realistic

However, we welcome the principle that people with learning disabilities should be assessed and treated quickly and have shorter stays in hospital. This requires effective liaison, support and in-reach of services known to those individuals and effective community-based support for them to move on from skilled staff who know how to support people with learning disabilities.

Loss of Slade Site as a Community Asset

We also have concerns about the potential loss of the Slade hospital site as we are concerned about the risk of asset stripping by Southern Health NHS trust if they do not continue to provide local services after the re-tendering process.

The tiers of support

The well-being and employment service.

We welcome an opportunity to explore how local businesses, charities, and statutory bodies could work to deliver a range of volunteering and work opportunities, apprenticeships and real jobs for people with learning disabilities. Currently, only 7% of people with learning disabilities are in work.

We want these services to realistically appraise what people with learning disabilities can do. We do not want these services to force people into work they are not capable of doing, but we want to aim high nonetheless for those who can volunteer or work.

Locally, we are aware that there is a dearth of opportunities for young people with LD who want to leave school and get a job. This needs to be addressed within both Children and Young People's services and Adult Services.

We challenge the local authority and local hospital and GP services to think about how they can commission local services that people with learning disabilities can do, such as catering services, estate maintenance services, routine office services.

We also would welcome an exploration of setting up local micro-enterprises, with support from the local business community and

voluntary sector to ensure that they are advised and supported to be sustainable.

Tier 1

The universal preventative service in tier one needs further clarification. Where will it sit- who will be part of this preventative service?

What is the remit of this preventative service?

What is the care pathway for someone with a learning disability approaching OCC for help?

Tier 2

Tier two refers to the First Response service. We strongly recommend that experienced staff from health and social care take on this triaging role to ensure that people do not slip through the net and are moved on quickly to the correct support.

Tier 3: Learning Disability Health and Social Care

It is not clear from the document what the "Health" role is within this tier, as there is almost no mention of any health roles, except a brief mention that it would include specialist nursing and would be provided by a specialist health partner. Our concerns are:

1. There is considerable evidence that people with a learning disability have a higher incidence of a number of related, and co-existing health conditions (individuals with complex needs) than the general population.
2. There is a wealth of evidence that people with a learning disability die younger (The Confidential Inquiry into Premature Deaths of People with Learning Disability).
3. There is considerable research describing the need for specialist health input to both support mainstream health service, and to provide expert knowledge and skills in directly treating and supporting people with a learning disability.

It is not clear from the limited information in The Big Plan that real consideration has been given to the complex health needs of people with a learning disability, and whilst supporting mainstream health services to

make reasonable adjustments, this will not address the specialist clinical knowledge and skills that have been developed by specialist health clinicians who directly support individuals with complex needs.

Tiers 3 and 4

How would people with high levels of be identified and then moved to tier 3 and 4?

We welcome the concept of an intensive support team, with an additional short break resource for people who have high levels of need as families in these situations feel strongly about the need for breaks in order to maintain caring.

Respite care

We understand that development of more community-based respite services such as Shared Lives is being proposed. Locally, it has been difficult for families to obtain these services as many Shared Lives families are offering long-term care for people with LD.

Similarly, we know of families whose relatives are seen as more challenging who do not receive support from these services.

Some families have expressed concern about the wide range of ages in residential respite care. A more tailored approach for younger people would be helpful.

Without taking on more professional carers, and having a dedicated short breaks service, there will still be issues of capacity. There may still be a need to provide an additional emergency respite base, whilst addressing some of the issues that lead to crises, such as the level of supported living available when an older carer dies and their relative needs housing.

More effective planning around the numbers of people who are likely to need these services needs to be carried out.

Some people will still need a more specialist environment because of profound LD or challenging behaviours. We do however feel that more innovative solutions, such as those provided by Yellow Submarine, have great potential to provide high quality, innovative breaks. The service

sadly relies heavily on fundraising for children's breaks to ensure that adult breaks are viable.

Transition

The document recommends that transition support sits with Children and Young People's services.

Whilst this seems right that the focus should sit there, there is no reference to how the overlap from 18-25 years will be managed in adult services and how Education, Health and Care plans will be implemented and monitored in adult services.

Currently, there are posts in both children's services and adult services to ensure that transition is managed reasonably smoothly. It is not perfect, but on the whole it ensures that people do not fall down the cracks. Who will take responsibility within OCC and OCCG for this in adult services?

Day Care

We recognise that most younger families would prefer to see community-based day services, so that young people can be supported to be part of their local communities.

The work of organisations such as MacIntyre No limits show how high quality support with skilled qualified staff can support young people with high levels of need.

The work of Yellow Submarine also demonstrates how local services can deliver effective support to young people and provide a strong connection with local communities.

However, we do recognise that the traditional models of day centres provide respite care that is vital for older carers and a trusted and supportive community for people who use them. We do not want to see older, more vulnerable family carers under greater pressure at a time in life when they need increasing support. This group in particular, would benefit from a dedicated support service, to set up holistic support especially if market forces cause the local day services to become unviable.

People with PMLD also need to be able to have meaningful day activities with staff that are particularly skilled in supporting both their physical care, their need for maintenance of skills and their communication. A major challenge is to deliver this without the need for a specialist environment, as there are a few places in Oxfordshire that are able to cater for the needs of people if they are out and about in their community.

Community Connecting

We welcome the possibility of the wellbeing and Employment Support Services exploring how communities can build up networks to support each other. We are aware of national projects such as Community Connections set up by The Foundation of People with Learning Disabilities (FPLD) who can advise, support and train people to become community connectors.

We think it would be a useful exercise to have Community Connection Workshops, using person-centred planning tools, to enable people to build up vital networks quickly.

We also would welcome setting up a network of Circles of Support- not the same as the Age UK model, where the emphasis there is on supporting discharge from hospitals, but to ensure that people with LD have friends and supporters in their lives who are not paid supporters.

Inclusive Solutions at Nottingham have also set up inclusive intentional communities that we could look at.

We also would welcome support for further development of Safe Places Schemes, Oxfordshire, that provide Safe Places in shops and local community resources such as libraries, well-being centres, leisure centres etc. to provide support to vulnerable people whilst out in the community. This provides a low level of safeguarding by the community for all vulnerable people. OxFSN have been working with partners in Banbury, Wantage and Didcot. The scheme needs a dedicated worker who can build this up with partners and sustain it, but the model in Banbury particularly is developing some strong partnerships.

Monitoring of outcomes and impacts for this strategy.

We recommend that, given the radical nature of these proposals that there should be close monitoring by a number of agencies:

Healthwatch, the Health and Well-Being Board and that a Strategic Advisory Group is set up to monitor the impacts of these strategic changes if implemented. This should include clinicians, social care professionals and a range of carers and people with learning disabilities.

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