# A Local Experience of National Concern

A scoping study into the information, advice and support needs of families who have relatives with learning disabilities, challenging behaviours and mental health needs

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This research was funded by Healthwatch Oxfordshire

This report is dedicated to the memory of Connor Sparrowhawk

Born 17/11/94 Died on 4/7/13

He was 18 years old when he died in a secure unit run by Southern Health NHS Foundation Trust in Oxford.

An independent report produced by Verita concluded that his death was preventable (1)

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# Executive Summary

Our aim in producing this report is 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.

We also explore a model of peer support, providing advocacy, information and support, developed by experts by experience, the families themselves.

We look at the national and local context of service provision to people with learning disabilities who use mental health services. We found that national research into the characteristics of people using secure mental health units showed that two-thirds of people have behaviours that challenge, rather than an identifiable mental illness (2). The local Winterbourne Concordat statistics show that the majority of people admitted for challenging behaviours were young men on the autistic spectrum (3).

## How we carried out this work

Our qualitatitive research shines a light on the local experiences of families on a daily basis, highlighting some of the challenges they face and the gaps in information, advice and support.

Our aim was to use this scoping study to identify:

1. Support families felt that they needed and identify potential gaps to assist in developing an action plan to shape the training and support OxFSN delivers as an organisation

2. The information, advice and support that would help to make both access to services and treatment easier to understand and use

3. External factors that affected the experiences of the families e.g. transition from children's services to adult services

We held three focus groups, one with Bill Mumford, the Director of the National Winterboune View Joint Improvement Programme, and local families, plus two other focus groups with families. We carried out interviews with 15 family carers plus interviews with family carers who have relatives with high functioning autism and challenging behaviours. We also met with Dr Barbara Coles who is a researcher in this field and is an expert by experience.

We asked four questions :

1. What information and support would help to make both access to services and treatment easier to understand and use?

2. What support and information works well and what does not work so well?

3. What would improve the experience of families?

4. What external factors can be identified that affected the experiences of the families e.g. transition from childrens' services to adult services?

## Peer to peer advocacy

We explored a model of a peer support service that includes advocacy, information and training. We gathered the responses from families to this concept. An outline of this model was then developed.

## Summary of key recommendations

### 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

### *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 (4)

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

## *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

## *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

## Next Steps for Oxfordshire Family Support Network (OxFSN)

1. We are seeking funding to work with national voluntary partners to enable there to be more detailed scoping work on the development of a peer to peer network of support and advocacy for families. Some of the requirements of peer advocacy are explored further in this report

2. We propose that Oxfordshire to be a potential pilot area to test out the peer advocacy and support model

3. A key priority for OxFSN as an organisation is to continue to work to ensure that families and professionals are trained in person-centred approaches

4. We want to see real changes in the way that services work with families so that families are seen as part of the solution and not part of the problem

## Change is not an option - it must happen

*"If anyone can effect change in the way in which learning disabled children / adults are treated, I'd lay my money on a bunch of (raging) mothers of disabled children"*

Dr Sara Ryan, mother of Connor Sparrowhawk

# Who we are

Oxfordshire Family Support Network is a registered charity set up by experts by experience. We are parent carers of people of all ages with learning disabilities.

We provide independent information, advice and support by families for families of people with learning disabilities.

Set up by family carers who wanted to use their experience to help others in the same situation we strive to improve the lives of people with learning disabilities and their families.

www.oxfsn.org.uk

# Acknowledgements

Oxfordshire Family Support Network would like to thank Oxfordshire Healthwatch for funding this research.

We would also like to thank all the families who took part in this study who shared both positive and painful experiences of supporting their relatives with learning disabilities, mental health needs and/or challenging behaviours. All were driven by a desire to improve the experiences of other families who face similar challenges.

In particular, we want to thank Dr Sara Ryan, who, despite facing the overwhelming loss of her son, Connor Sparrowhawk, has given us her support, and inspired us to do this work. We also want to thank her for giving us permission to use her photograph of Connor and to use the image of one of his artworks on the front cover.

We also wish to express our appreciation to Bill Mumford, Director of the Winterbourne Joint Improvement Programme for meeting with us and contributing his perspectives.

Thanks are also due to the volunteers who have given their time to help with this project in a variety of ways, including Dr Janet Read, Cathy Score, Frances Steepe and our Chair of Trustees, Yvonne Cox.

Thanks are due to Dr Barbara Coles, who also advised us on this project, who is an expert by experience, as well as an academic working in the field of learning disabilities and challenging behaviour. She kindly shared her recent unpublished paper on the support needs of families who have relatives with these complex needs (6).

Finally, thanks to Laura Medlar, and Emma Sims, student social workers at Oxford Brookes University who are on placement with Oxfordshire Family Support Network and helped with interviewing families.

# Background

## Why did we choose to do this research?

Oxfordshire Family Support Network wanted to carry out a small scoping piece of research on the experience of families that have relatives of all ages with learning disabilities who have mental health needs or behaviours that are seen as challenging. There may be a dual diagnosis of autism. Our aim was to find out how their information, advice and support needs as families can be better understood and improved.

These families often experience considerable difficulties and have high support needs over long periods of time. Many may end up facing crises with their relatives. In some cases, their relatives may be admitted to secure units for assessment and treatment, after being sectioned under the Mental Health Act 2007 (7). They may be admitted to private hospitals like Winterbourne View or equivalent NHS facilities. Some may be placed in residential care. Children and young people may be living far from home either in adolescent secure units or else in residential special schools.

This complex mix of very high needs can result in considerable challenges in obtaining the right help in a timely fashion and many families live on the edge of crisis as a result, sometimes on a daily basis.

## Is there a need for support to families?

### The national context

There is now recognition nationally of the level of need amongst this group of children and adults and their families. There is also increasing acknowledgement that provision for them is often inappropriate, inadequate and in need of reform and development.

1. "*People with learning disabilities and family carers are often unfamiliar with how mental health services are delivered and find it difficult to access and navigate them. They are therefore less likely to seek help for mental health problems and, when they do present for whatever reason, problems are more likely to be attributed to their learning disability (diagnostic overshadowing) or classed as challenging behaviour" Source - Foundation of People with Learning Disabilities* (8)

2. "*Research has shown that up to 40% of people with learning disabilities experience mental health difficulties. They are often unable to get support from the appropriate services" Source - Foundation of People with Learning Disabilities* (8)

3. "*Prevalence of anxiety and depression in people with learning disabilities is the same as for the general population, yet for children and young people with a learning disability, the prevalence rate of a diagnosable psychiatric disorder is 36%, compared with 8% of those who do not have a learning disability." Source - Foundation of People with Learning Disabilities* (8)

4. The Chief Medical Officer (CMO) for England's latest report comments that for *all* children and young people 75 per cent of lifetime mental health disorders start before 18 years of age, with the peak onset of most conditions being from 8 to 15 years. This points to the need for early and timely intervention.

   This report from the CMO states that attention needs to be given to "*How to meet the needs of particular groups of children and young people for whom provision has been very unsatisfactory. This includes children and young people who have learning disabilities and mental health issues, including challenging behaviour. A programme of research is urgently required, designed with children, young people and their families, to identify effective provision that would meet these needs* (9)

5. The recent national public enquiry into the abuse of people with learning disabilities at Winterbourne View, highlights the issues about the limited support for people with learning disabilities with such complex needs (10)

6. In 1997, Prof Jim Mansell wrote a report about the need to improve support for young people and adults with learning disabilities and challenging behaviours or mental health needs. He revisited the issues ten years later. He commented: "*Although there has been good progress on many fronts since the publication of Valuing People, progress in respect of challenging behaviour has lagged behind. The failure to develop appropriate services has led to an increase in the use of placements which are expensive, away from the person's home and not necessarily of good quality. The main reason for this is that commissioning has been too reactive and has therefore become dominated by trying to manage crises. What is needed is for Councils to strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop services for individuals so that they are ready when needed. This is entirely consistent with the Government's focus on personalisation and prevention in social care."* (11)

7. In 2014, we have to ask if the outcomes for people with learning disability with mental health needs or challenging behaviours have significantly improved or not. It feels like there are still significant gaps in creating personalised support that is working and that families are still struggling trying to get to get access to the right information, advice and support. It is important to ensure that their relatives have good support and services, with positive outcomes.

8. Dr Sara Ryan comments in her blog: "*The acceptance of the unacceptable is common when you're a parent of a disabled child / adult. Well, and among commissioners, providers, health and social care professionals, support workers and so on. Particularly in the fabric of "learning disability provision". The bar set so low that accepting mediocre becomes a default position. We're almost socialised to create an ever present bag of excuses and rationalisations for non-existent, inappropriate or partial services*" My Daft Life – Accepting the Unacceptable (12)

9. On the support needs of family carers, Professor Mansell comments that families need "*advice and training for family members in how to understand, interpret and manage situations the person finds challenging..*". He recommended using personalised solutions to achieve better outcomes. He continues "The results of giving families resources to organise their own support, through self-directed services such as "In Control", seem to be much better than those achieved by traditional home care services " He adds. "*Services exist to meet the needs of their users; but, within this framework, the needs of carers should also be considered to be very important, both because services cannot succeed without the contribution made by carers and because as a matter of principle one group of people's needs should not be met at the expense of another. Of course there will be important conflicts of interest between service users and their carers which will need to be faced up to at an individual level*". (13)

10. Research by Emerson and Einfeld shows that the 10-15% of people with learning disabilities who show challenging behaviours are more likely to experience "*increased risk of exclusion, physical injury, abuse and harsh restrictive management approaches such as physical restraint*" (14)

## Mental Capacity Act 2005

1. The Mental Capacity Act, when introduced, was heralded as a highly significant step forward in securing the rights of people who may lack capacity and it is still rightly seen as being central to the appropriate support, well-being and safeguarding of people with learning disabilities and their families. However, in recent times, there has been increasing criticism about the way in which the Act has been used and about the fitness for purpose of the Deprivation of Liberty Safeguards. Indeed in March this year, the House of Lords Select Committee, having been tasked with identifying whether the Act was working as Parliament intended, issued a Report of the findings of their scrutiny of the Act (15)

2. *"Vulnerable Adults are being failed by the Act designed to protect and empower them. Social workers, healthcare professionals and others involved in the care of vulnerable adults are not aware of the Mental Capacity Act, and are failing to implement it"* (16)

3. The findings in this Report have revealed a widespread lack of understanding of the fundamental principles of the Act by professionals in both health and social care and a lack of availability of information for families and carers of those lacking capacity and so a lack of understanding of their rights.

4. "*The general lack of awareness of the provisions of the Act has allowed prevailing professional practices to continue unchallenged, and allowed decision-making to be dominated by professionals, without the required input from families and carers*" (17)

5. The Report makes several references to the need for improved information to be made available to professionals and families alike. In particular it acknowledges the role of independent third sector groups in this area "*many witnesses pointed to the importance of the voluntary sector in disseminating information to service users and their families*" (18)

6. One of the principal recommendations of the Report therefore is that the Government as a matter of urgency addresses *"the issue of low awareness among those affected, their families and carers, professionals and the wider public"* (19)

7. The findings of the Report make clear how important it is that families understand the workings of the Mental Capacity Act in order to safeguard their relatives and to challenge bad practice.

8. The Report reserved its strongest criticism for the inadequacies in the implementation of the Deprivation of Liberty Safeguards and strongly recommended a comprehensive review and ultimately redrafting of the provisions which were universally found to be excessively complex.

9. "*Legal safeguards were rightly set up several years ago to ensure that people who lack capacity are only deprived of their liberty when it is in their best interests and all less restrictive options have been explored. However, the system established to do this is bewilderingly complex. The current safeguards are underused, leaving the rights of many vulnerable people at risk*" (16)

## Winterbourne View and its aftermath

The Government Report, " Transforming Care - a National Response to Winterbourne View" identified criminal acts of abuse against vulnerable people in a private hospital called Winterbourne View, run by a company called Castlebeck. The report highlights systemic failings in the way people were treated there. In particular, they found:

1. "*Warning signs were not picked up or acted on by health or local authorities, and concerns raised by a whistleblower went unheeded."*

2. "*Though individual members of staff at Winterbourne View have been convicted, this case has revealed weaknesses in the system's ability to hold the leaders of care organisations to account. This is a gap in the care regulatory framework which the Government is committed to address*".

3. *"The abuse in Winterbourne View is only part of the story. Many of the actions in this report cover the wider issue of how we care for children, young people and adults with learning disabilities or autism, who also have mental health conditions or behaviours described as challenging."* (20)

### Advocacy Support

Advocacy has increasingly been identified as a key service for vulnerable adults, children and their relatives with formal and informal advocates having a important contribution to make. Inclusion North's report *Who Cares* state *"Informal advocates such as family and carers play an important role in looking out for people's interests; it is unacceptable for their views to be ignored or dismissed. All services should have a clear policy to support their involvement in care planning."* (21)

They also recommend *"Commissioners should ensure that there is appropriate on-going access to advocacy in residential settings. This should not be solely dependent on receiving referrals."* (21)

Their research also flagged up that people with learning disabilities and their families sometimes *"experience professionals and organisations in their lives that behave as if only they 'know best'"* (21)

These attitudes can become massive barriers to change in the prevailing culture.

We will explore the role of advocacy for families further in this report.

## The Oxford Context

Locally, the tragic death in July 2013 of Connor Sparrowhawk, in the Short –Term Treatment and Assessment Unit run by Southern Health NHS Trust in Oxford, made us all too painfully aware of the importance of families getting the right information, advice and support, in order to know how to safeguard and protect their loved ones.

In addition, three individuals from Oxford were placed in Winterbourne View and suffered abuse there.

Families have to navigate systems of care and support that are complex and confusing. Professionals and families alike may have strongly differing views on the reasons why people with learning disabilities, demonstrate challenging behaviours. This only adds to the difficulties that families face in trying to find ways to get a better quality of life for their relatives.

After the BBC Panorama programme revealed the appalling abuse at Winterbourne View, the Government requested that a local Concordat was set up in all 152 Local Authorities with the express aim of identifying where people were placed and to develop action plans to bring them back into county where possible.

Currently, the multi-agency task group, the Oxfordshire Winterbourne Joint Improvement Concordat meets and has a draft report that is close to completion.

The aim is to identify the numbers of people who are in secure units and other placements that are out of county and to develop an action plan to put alternative supports in place within county to bring people back into county where possible.

The local Winterbourne Concordat draft report (3) stated that:

1. Over the last 3 years (January 2010 to December 2013) 45 people have been admitted into Assessment & Treatment Hospitals (like STATT).

2. Most people were admitted because they had mental illness or challenging behaviour (mostly with autism).

3. A very small number of people were admitted because of substance misuse (drugs and alcohol) issues.

4. The people who were admitted because of challenging behaviours were almost all men with autism and most often in their early 20s.

5. Both men and women were admitted because of poor mental health. The average age of this group of patients was 38 years. The youngest person was 18 years old. The oldest was in his 70s.

6. The same report fed back that NHS England had identified gaps in services in the South-East region for:

    - Health services which can provide nursing support to people for short periods of time when their behaviour is very challenging.

  - Health services which can support people in the community when there is a crisis.
  - Services for people with autism.

We have also been informed that a total of 87 people are on the Care Programme Approach (CPA) (22)

# Definitions

## Mental Health Needs

We mean that people with learning disabilities may have recognisable psychiatric disorders that affect the way people think, feel or behave, as defined by diagnostic criteria used by the Royal College of Psychiatrists in the UK (23)

For example, they may experience depression and anxiety or may have complex mental health needs such as bi-polar disorder or schizophrenia for example.

It is often more challenging to support a person with learning disabilities, autism, and mental health needs as they may be unable to verbally communicate effectively to others about their mental distress.

## What do we define as challenging behaviours?

Prof Eric Emerson (1995) defined challenging behaviour as *"Behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be put in jeopardy, or behaviour which is likely to limit the use of, or result in the person being denied access to ordinary community facilities."* (24)

*"In essence it is that there is something going wrong that needs to be addressed, not that there is a person doing something wrong who needs to be stopped……It is the impact of these behaviours that makes them challenging, not any judgement about their appropriateness."* (25)

A number of the families we spoke to held the view that their relative did not have mental health needs but did have severe communication problems that resulted in them developing severe challenging behaviour. They identified the cause as frustration at being unable to convey their needs to others. In some cases, their autism contributed to sensory overload.

These definitions themselves are evidence of the ongoing debate about causation and treatment of challenging behaviours and mental health needs.

## Care Programme Approach

The Care Programme Approach or CPA is a national system that sets out how people with mental health needs who have complex conditions are supported. Under the CPA system, people are entitled to have a detailed assessment of their health and social care needs, a detailed care plan drawn up, and regular reviews. A CPA co-ordinator is appointed who may be a social worker, or community psychiatric nurse, or an Occupational Therapist (26)

# The Scoping Study

## Aims

Our aim was to use this scoping study to identify:

1. Support families felt that they needed, identify potential gaps, to assist in developing an action plan to shape the training and support we deliver as an organisation

2. Discover the information, advice and support that would help to make both access to services and treatment easier to understand and use

3. Identify external factors that affected the experiences of the families e.g. transition from children's services to adult services

We wish to test the need for peer-to-peer support and the development of information by experts by experience, driven by the needs of families. We wanted to gain an understanding of how this could best be delivered and what this support service could look like. We explore the realities of personalised support, based on the experiences of families.

This is a small-scale scoping study that identifies some key issues for further work.

***In short, it is about the local experience of a set of issues of national concern***

## How we contacted the participants

We sent out information about this study to:

1. the manager of the learning disability teams

2. to the commissioner working on the Winterbourne Concordat locally

3. to the individual learning disability teams

4. heads of special schools

5. local learning disability voluntary sector groups

6. all learning disability day services run by OCC

7. the Oxfordshire County Council Family Information Service who produce a weekly bulletin

8. the Children’s Disability Team

We advertised on our Facebook Page and it was also tweeted by a number of our followers.

## Face-to-face work with the family carers who participated

### We held 3 focus groups:

1. The first one was with Bill Mumford, the National Director of the Winterbourne View Joint Improvement Programme, who generously offered to meet with us. It consisted of a group of parent carers of adults and young people with learning disabilities, some of whom were on the autism spectrum and volunteers from Oxfordshire Family Support Network

2. The second was with a group of younger parents whose children and young people were at school

3. The third was with some of the parents who attended the first meeting with Bill Mumford

### We carried out individual interviews

We also carried out a small qualitative study, using semi-structured interviews with 15 family carers where either a young person or an adult with a learning disability within their family has shown either behaviours that challenge or who has mental health issues.

We interviewed one parent living in another county who has extensive knowledge of these issues from his national work on challenging behaviour.

We interviewed 3 families who had relatives who were on the autistic spectrum who had higher functioning autism to explore if there were common issues.

We wanted to find out from all these families what their experiences were of using specialist (and where appropriate) mainstream mental health services. The aim was to explore the pathways that families took in seeking support and to understand the information, advice and support they received along that journey.

The interviews were based around a topic guide which had been designed in consultation with families with relatives with learning disabilities (Appendix 1)

The majority of our participants came through family networking.

There were a variety of experiences across all the participants. Some have the experience of relatives who are placed out of county - either in residential schools or homes, or in else in psychiatric units. Some have been in secure units within NHS provision and some within private hospitals.

We also interviewed families who have had relatives who had been in secure units under Mental Health Act section but who had seen their relatives moved back into the community with success (27)

We met with Dr Barbara Coles who had carried out her PhD research on 12 families nationally who had used Direct Payments to provide support in community-based settings. Her participants have relatives who have these very complex needs and learning disabilities. She is herself an expert by experience as she has a son with learning disabilities (6)

## Key questions we explored

1. What information and support would help to make both access to services and treatment easier to understand and use?

2. What support and information works well and what does not work so well?

3. What would improve the experience of families?

4. What external factors that can be identified that affected the experiences of the families e.g. transition from childrens' services to adult services?

# Findings

## First Focus Group

At our first focus group, we met with Bill Mumford, Director of the National Winterbourne View Joint Improvement Programme.

He shared valuable insights into the challenges that families face in getting advice, support and information for their loved ones:

1. Whilst the provider and staff were clearly culpable at Winterbourne View, there is clear need to address underlying issues regarding failing services which lead to the institutionalisation of vulnerable people. The current model of service must be challenged (10)

2. The Department of Health responded with the publication of the Concordat which set out a wide programme of work and proposal to reduce dramatically the number of inpatients (28)

3. There remain approx. 3,250 inpatients with learning disabilities - there has been no reduction of numbers in assessment and treatment units. Of this number more than 50% have been inpatients for more than 5 years – so it is apparent that these units are not fulfilling their role for assessment and treatment as people are not moving on (2)

4. He felt that view that there must not only be a reduction in numbers but that treatment in units must be therapeutic and that pathways to crisis must be addressed

5. ***Of the 3,250, at least two thirds of those with learning disabilities are not ill but have behaviours that challenge***

6. The Department of Health Report "Winterbourne View - One Year On" published Dec 2013 has made it clear that very little progress has been made. The discussion should be driven down from national to local - to a person by person level (29)

7. At present 50% of patients are funded locally (Local Authorities and Clinical Commissioning Groups), 50% are funded by NHS England (29)

8. ***Serious problems remain around transition nationally***

9. Questions need to be answered as to why forward planning is so problematic and how to ensure that children with complex needs have bespoke plans that can be translated into something workable

10. It is clear from Winterbourne View that every individual should have a care plan but one which must be translated into a service which works

11. Bill Mumford recommended that there should be a pro-active project management service available to implement effective care planning. The onus should not fall on the parents to drive this process

12. More generally he felt that there was a pressing need to rethink community support

13. NICE are working on Guidance regarding assessment and treatment units so that Commissioners know what standards to expect and can effectively evaluate providers

One family carer expressed frustration at short term view of politicians who have control of budgets, who fail to understand the long term implications of decisions for young people with learning disabilities who have complex support needs.

Bill Mumford recognised this as a potential problem and confirmed that there is evidence to show that interventions before crisis might be costly in the short term but be more efficient in the long term.

Locally, some parents praised the support they had received from No Limits, a scheme run by McIntyre and felt this was a much more creative and effective approach.

Short-Term Treatment and Assessment Units (STAT) are very expensive and a service such as No Limits may be expensive in the short term but is much cheaper than STAT and will lead to reduction in costly service over time.

There were concerns that commissioners are not able to identify good services and that private providers may dominate and distort the market. A parent expressed similar concerns from experience about private providers effectively being run by accountants.

Bill Mumford acknowledged the potential disconnect between commissioners and those providing services. He noted that inpatients were placed fairly equally between NHS and private providers (there were very few voluntary organisations) - and in terms of CQC compliance there was no evidence of either type of provider outperforming the other.

Bill Mumford identified three key tasks for his work in the next 18 months:

1. Reduce number of inpatients - engage with families and look to appoint someone to project manage rehabilitation
2. Use the experience of effective rehabilitation and apply to families in crisis – on the cusp of admission, to limit time in Assessment and Treatment Units
3. Seek to build up expertise and support families effectively before it all goes wrong

Families were concerned that professionals themselves are often poorly informed and emphasised the fact that they felt families are not listened to in these secure units.

One older carer has battled the system since the birth of her son in 1958. From experience she has found that professionals often have very little understanding of the interaction of learning disability and mental ill health and seemed unable to understand that her son's mental health condition was distinct from his learning disability.

She knew he was severely depressed but professionals assumed his lack of responsiveness and poor communication was a result of his learning disability.

One parent explained how Direct Payments have worked very well for some people in designing their own service but that when funding moved to continuing health care their services have been changed. Families members are taken out of the equation and the Mental Capacity Act has been used to alienate families with families having no option but to make applications to Court of Protection.

Bill confirmed that there is movement to personal health budgets (With effect from April 2014 Personal Health Budgets will be available for those awarded Continuing Health Care).

Several families had experienced challenging practice when relatives were not doing anything therapeutic. This was justified on the grounds that they had capacity and were making informed choices.

A number of families highlighted problems encountered after their child turns 18 - when Choice and Control (and the Mental Capacity Act) is used by professionals to disengage families. There were concerns both about the judgement about how relatives were assessed as having capacity and about the quality of such assessments.

Their experiences were backed up by the evidence supplied to the House of Lords Select Committee: *"The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult.* (17)

Other comments from parent carers:

1. Information about the failings of the Oxford unit was theoretically available but families need to know what to look for. Commissioners should have spotted failings in the Oxford unit

2. Parents are very vulnerable - it is very difficult to be assertive without jeopardising care for the relatives - there is a fear of antagonising staff

3. One parent suggested use of mystery shoppers in units

4. One carer described her experience when her son was sectioned. Even when appropriate questions were asked by well informed people at a Tribunal no proper answers were given. She also raised the issue of concern about continuity of services. Even though support may be working at a given time, there is always fear that the service will change, and deteriorate. Her son's challenging behaviour arose as a result of his anger because the service he was receiving was inappropriate

5. Providers need to be made to be more family friendly - families should not be labelled difficult for expressing concerns

6. Use of CCTV in unit had proved very useful for one family as it had shown an incident which had lead to abusive behaviour. However it took the family 4 months to obtain the evidence. It was suggested the footage could be used for training to reveal poor practice

7. Families highlighted the scandal that some Winterbourne View inpatients had been moved to other institutions where further abuse occurred

## Second focus group

A group of younger parents met with us at a special school - their children and young people came from different schools, including an out-of-county residential school and a mainstream school. Their observations were as follows:

1. Waiting times at different services for appointments proves a problem as parents arrive at an appointment at the right time but have to wait with their child, often for a long time, before being seen. This often causes distress
2. It was felt that at times professionals only seem be interested in the diagnosis
3. Interventions for families are often short-term. The parents described not experiencing follow up and once they have finished with a service it is hard to get back into it again
4. Services are perceived as often only being reactive rather than proactive. Families described having to hit crisis before being able to receive any support.
5. Professionals often do not see the bigger picture as their roles are specialised. They are only concentrating on one problem rather than seeing the person as a whole. Families felt that their child often "becomes lost in the diagnoses."
6. One parent in particular had experience working within Learning Disability services and so felt she knew where to go for support; however she acknowledged that people who did not have that experience would not know where to look. *"It's not what you know, it's who you know".* This was a view shared by two older family carers we spoke to.
7. The parents acknowledged that most of the useful information they receive comes from other parents and their experiences. They felt they needed better signposting towards appropriate support from professionals and services.
8. The parents suggested that information about support should first come through GPs. However they felt that they did not always seem to have the right knowledge.
9. Waiting lists for support are so long that when you are then able to access the support you either do not need it anymore or you have then reached a crisis point.
10. It was felt there should be one accessible person within the system that you can contact to find out where to get support.

11. 'You don't know what you don't know'. It was felt nobody came to families to inform them of their rights.

Below is a summary the barriers and solutions that young families identified in order to meet their information, advice and support needs.

### BARRIERS & SOLUTIONS IN SUPPORTING CHILDREN AND YOUNG PEOPLE WITH CHALLENGING BEHAVIOURS AND MENTAL HEALTH NEEDS

| | | |
|---|---|---|
| Children who are not in special schools find it harder to access information<br>More information being passed from school to homes | Discrimination when your child has 'challenging behaviour' or needs medication to be administered<br>Behaviour and health support plans<br>Wider use of Out of School Liaison Officers | It can be difficult to find people that you can employ using a direct payment and it can often be harder work<br>A training manual which could be accessed online<br>Being able to access resources through networking |
| Transportation is often high in cost, especially when 1:1 support is needed | Staff are not always highly trained<br>Skilling and training people more – maybe those who are new to the work | Isolation and Loneliness<br>Meeting other families as a way of sharing information – feel like you are not on your own |
| Having to meet a certain criteria<br>Intervention earlier and more continuity of support | Not having a statement 'special educational needs'<br>Support available for anyone within the school with a need<br>More information sharing between services | Not knowing where to access information such as what your rights are<br>More courses for families – advice and training<br>Services making contact with families through schools e.g. newsletters<br>Support being offered through a central point of contact |

Comments from other young families we interviewed individually:

1. C’s parents attend regular Team Around the Child (TAC) meetings, however they said “*there is often poor attendance from the professionals who should be there. … there needs to be a higher number of people turning up to the meetings*”

2. They also said that for many services they felt that they did not fit the criteria and were therefore missing out on services which may have been beneficial for them

3. This family had also had a very stressful time organising their child’s transition to secondary school. Parent Partnership support was critically important in obtaining a good outcome. They eventually moved him from mainstream to a special school

4. Getting professionals to take concerns seriously can be an issue…

“I told them that his moods were cyclical – I was told he is not pre-menstrual!” Mother of an 18 year old with bipolar disorder

## Third Focus Group

The third focus group consisted of 8 people who had previously attended the Focus Group with Bill Mumford. The group focussed on barriers to obtaining information, advice and support and worked on solutions, in order to identify gaps in support and to assist in answering the question, “What could a peer to peer support service look like?”

| Barriers | Solutions |
|---|---|
| Difficulty in getting into system | Better information about pathways and processes, having one point of contact |
| Eligibility criteria too high | Lower thresholds for offering support before crisis - consider the role of the voluntary sector |
| Difficulties in getting staff with sufficient training | More accredited training for staff caring for people with complex needs, develop quality standards, develop pool of skilled staff, online information sharing |
| Not knowing where to access information on rights of relatives and carers | Information sharing through a central contact point |
| I did not know I could have an advocate and that my child could | Information on rights / advocacy and support in key meetings |
| Mental Capacity Act - what's that? | Every parent who has a child with a learning disability to be given information and to be invited to workshops on MCA - and in hard to reach groups, identify MCA champions to reach them |
| Why was my option in a crisis to phone the police - why no crisis team information given to families | A crisis team point of contact that does not require people to work through layers of bureaucracy to get there, that is given out by GPs / Schools / etc to families who have young people who have challenging behaviours / mental health needs |

| **Barriers** | **Solutions** |
|---|---|
| Why does everything change so drastically at 18? - choice overrides learning disability. Mental Capacity Act changes all | Better information and training for parents and for professionals in how the Mental Capacity Act should be used |
| Transfer at transition for young people with mental health problems - who to call? - what are my child's rights to support? | A local point of contact through peer to peer support |
| Resources and professional time | Nationally, the Govt needs to make "Invest to save" funding |
| Power imbalances between clinical staff and other professionals | Training through the Royal Colleges and development of different models |
| Lack of communication and openness of staff | Develop a family-friendly culture, develop clear processes that make it easy to ensure families are given the opportunity to share information, and work in ways that enable families to maintain family bonds when it is in the best interests of the person involved- assume default position of involvement unless strong contra-indications |
| Why is there no facility in county to assess our children who are under 18 - why no local beds? Threatening he has to go out of county | There has to be investment in building local support that is ideally geared up to young people up to the age of 25 |
| Power imbalances between families and professionals in secure units | This requires top-down cultural change - it needs to start when medical staff are being trained, in order to both respect and make best use of families' knowledge and expertise |
| Problems with recognising the differences between learning disability and mental health needs - the risk of diagnostic overshadowing because mental health needs may be ascribed to learning disabilities | Better training for professionals, use of person-centred approaches that enable families' voices to be heard, better understanding of communication and sensory needs through careful assessment when a person shows challenging behaviours |

## Case Studies

### Case Study 1 – Fragility of Support

E has a teenage son with learning disabilities, autism and behaviours that challenge. He attends a residential school during term time.

E's son went through a number of special school placements, which ultimately failed as a result of his behaviours that challenged.

E searched 20 placements before they found a residential school that they felt would be able to support their son.

E commented that her son's behaviours are causing him to have decreased learning and social opportunities .The family are anxious about the fragility of the support and the lack of real options for him.

His parents are concerned and saddened that the school has to use physical restraints which they do not use at home.

Their son is an absconder and needs 2:1 supervision which is highly stressful. His mother described how they had to have a police helicopter search on one occasion. His sleep is very poor so when he is home, it can be tiring for the family.

The family feel that they need information around the options open to them to support their son in the future. They also would like information about how to use Direct Payments and self-directed support to create opportunities for their son that are tailored to his needs, particularly in the school holidays.

E had little knowledge about the Mental Capacity Act and about Best Interests meetings and their role and rights once their son was over 18.

They welcomed the idea of a model of peer support, and suggested that the Parent Partnership model, using independent parental supporters works well and that this type of model could be adapted, using trained supporters, for this more specialist area.

As a family, they felt that they could not talk about the life they and their family lived with "ordinary friends" as they felt it was so far away from their experiences that they would not understand.

## Case Study 2 – The difference good support has made to our lives

J is currently supported by MacIntyre No Limits and the formidable post 16 team at school.

In April 2012 following a crisis he was sectioned and hospitalised 170 miles from home for 6 months in a treatment and assessment unit. He now has a provisional diagnosis of Bi Polar as well as severe learning disability,

In October 2012, J arrived home on weekend leave as part of his discharge planning. In the previous 24 hours he had been restrained 3 times, and had received injuries to his face and legs, we were horrified by the state of him and did not allow him back to the hospital.

At that stage we were living in fear of what the future held for him and us, he had had a very traumatic experience whilst in hospital. No Limits were able to jump in, they had visited him in the unit, his package of care had been set up to start the day he was admitted to hospital (It took 18 months to put in place)

Today he attends school in the morning with 1-1 support to do community activities in the afternoon with his No Limits Community Learning facilitators.

Two years on he is growing in confidence, with the support from this amazing team who focus and balance his needs, wishes and choices. They have been key to his progress, they all know him well and have his best interests at the centre of everything they do, we are all part of the same team. With support he attends the Gym, swimming lessons, trampolining, travel training in conjunction with school, social clubs and 'The Compass Project' at The Yellow Submarine (YSM) café in Oxford, a fantastic charity with such great values, he is now asking to attend without the 1-1 support.

His March 2014 his report from this YSM was heart-warming, and sums up what good provision can do, it demonstrates the importance of the joint working and really valuing people, his report says his growth in confidence over the past 12 weeks has impacted in multiple ways: his participation has increased, he is socialising more with other members, and it goes onto say he has demonstrated initiative independently such as clearing lunch dishes away and delivering items and lunch orders to the café. For us this is fantastic especially as it has been during a time when he has been struggling a little, and last week he came home requesting to go on a residential trip with YSM, incredible when he has been reluctant to stay away from home since his hospital admission.

This all has a huge positive knock on effect for us as a family, not least because we are listened to, his voice is heard and we are no longer on our knees trying to get the right support for our son….long may it last!

## Case Study 3 – A prisoner but not a prisoner

D is a single parent, who has a son, R who she cared for 34 years at home. Increasingly, his behaviour became more and more controlling and demanding and he began to hit his mum.

The police were called and he was taken under police escort to a mainstream mental health facility where he was sectioned. He was there for a few days, but they did not know how to respond to his needs as a person with a learning disability. He was then moved to a secure private hospital which was a 13 hour round trip for his mother - he was there for over a year.

His mother's comment was "*It was the worst place imaginable for him. It was a shock to both of us. He had lived in his local community for years and had freedom to walk to his day centre by himself. He was a prisoner but not a prisoner. In my eyes, he was being treated like a prisoner."*

His family had not seen his bedroom until the care manager insisted they did. All of his clothes were on the floor as R refused to put his clothes away as he felt that if he put his clothes away he would never be allowed to leave.

One occasion, the family rang ahead to inform R that they were delayed. They arrived to find the message had not been passed on and he had been waiting by the door for an hour. He had then got impatient and attacked a member of staff, so when his family arrived they were told to come back the following week (this was after a 6 hour journey). D insisted that they saw her son and were put in a waiting room. They waited for 2 hours for the doctor to assess her son before they were allowed to see him. Eventually they saw him for about 10 minutes in the presence of a number of staff.

His mum had found him with bruising on a number of occasions. One time, she arrived to find that he had a very black eye. She was told he had had a seizure about 4 days before but had not been informed that he had had this seizure until she visited.

Her experiences changed when her son was eventually moved back to Oxfordshire when her son was admitted to a secure unit there run by the NHS. He began to go out, with support, into the community. The staff took him to his old day centre again. His mum was able to visit twice weekly. There was regular support from the psychiatrist who was an LD specialist. R was then moved into a residential home and lived there for 4 years. He then unfortunately assaulted a member of staff and was moved out of county to another residential home. Thankfully, he is now settled and for the first time feels truly at home since he was first sectioned.

When her son was taken out of county she lost DLA and carers allowance, meaning little finance to visit him.

## Case Study 4 – Struggle for a diagnosis and appropriate support

A is a young woman who has severe learning disabilities and also has bi-polar disorder. She lives at home with her family and has younger siblings.

Her mother described the terrifying impact of the first psychotic episode, as her daughter went out in the middle of the winter late one night, experiencing auditory hallucinations. As a result, her mother had a massive battle to get someone to see her. She said *"I was at my wit's end, I was exhausted", **"I haven't got an end of shift- I have a social service that works office hours".***

She rang her GP and was eventually referred to the Emergency Out of Hours GP and seen by one of the specialist learning disability psychiatrists. Her daughter is now well-supported by the learning disability team nurse and has responded well to medication, though her mental health needs still fluctuate and have an impact on the whole family's ability to cope, particularly when A is not sleeping well.

It has taken 5 years to get a diagnosis of bi-polar disorder from the time that A's mother tried to get answers about the changes in her daughter's behaviours.

A's mother feels that looking back, her daughter was experiencing problems from early childhood but there was no-one who took the issues seriously until she was older. Her mother felt ***"You dismiss your own gut instinct when professionals dismiss your worries…"***

She felt very strongly that schools need to be more aware of mental health needs. In her view, staff had no training in what to look for in order to identify that her daughter was experiencing difficulties and to achieve support earlier. A's mother did not think that key information was being passed between agencies and families and that this needs to improve.

She saw a peer support service offering:

- Regular, low–level checks through a local support group to ensure that all was well for the family
- support in the form of texts / information
- A's mother would welcome online support "A place to just vent"
- She felt that a peer to peer support network could provide useful ***additional support***, particularly when there was no on-going social work support as the care managers may change.

She needed skilled respite care workers, able to cope with her daughter's mental health needs.

She felt that there needs to be better monitoring of care quality and that there should be frequent, unannounced inspections, and widespread use of CCTV. Indeed, it was her anxiety about abuse that prevented her from taking the step of enabling her daughter to move into supported living, something she felt would be ideal for her daughter if it was not for this perceived risk.

## Meeting with Dr Barbara Coles

### *Direct Payments*

Prof Mansell in his report in 2007, felt that the use of self-directed support to purchase services, would lead to better outcomes. Dr Coles researched the experience of 12 families nationally who were using self directed support to create personalised packages of care for relatives who had learning disabilities and severe challenging behaviour (11)

Dr Coles expressed her concern that the drive to move people out of secure units should not be done at any cost, without developing suitable alternatives. The tight timescales on the Joint Improvement Programme, with only 18 months left to implement key changes to reduce numbers in Assessment and Treatment Units, suggests that care needs to be taken to ensure that there are good quality outcomes and that families are given the right information, support and advice to help them through this process. She found that families facing the challenges of trying to build good lives for their relatives and been heavily researched by academics but were offered very little by way of support that led to improved outcomes (30)

Dr Coles questioned the medical model that underpins the Continuing Health Care Funding for people with learning disabilities and challenging behaviours. In her research she had come across people who had a Direct Payment but who had then been moved onto Continuing Health Care. We understand that there are few people with learning disabilities who are receiving the new Personal Health Budgets (PHBs) in Oxfordshire but as Learning Disability Services have had pooled Health and Social Care budgets for a while, it is not clear whether PHBs will lead to any significant changes in the level or quality of support that families would receive.

In her view, User-led Organisations do not yet have the skills to support families in these complex situations. She commented on the inadequacy of resources, so that families are frequently plugging the gap and effectively shouldering the risks.

There are significant obstacles for families in getting information, advice and support to make best use of self-directed support for people with challenging behaviours. Finding personal assistants with the right skills who can deliver support to people with learning disabilities who have these very complex needs is very difficult. Whilst Prof. Mansell was right to recommend personalised solutions to meet the needs of people with learning disabilities, and behaviours that challenge, the reality is that families still have quite limited access to highly skilled support in community-based settings.

She rightly pointed out that unfortunately some families do not have the best interests of their relative at heart and that people with learning disabilties do need access to Independent Mental Capacity Advocates.

Dr Coles strongly emphasised the need for family carers to be given good information, advice and support in order to challenge poor practice and to achieve a good outcome. In her experience, families need to check treatment and support plans so that they become the critical thinkers, on behalf of the relative, where they lack capacity to make their own decisions.

## Key themes from individual interviews

### *Peer to peer advocacy*

Families recognise that in a crisis they would need professional support but would also welcome peer to peer support and advocacy. They would also value this type of support throughout the whole journey, especially during reviews.

Our qualitative research shows that the families we interviewed are desperate for support and information. They all recognised that they needed professional support for their relatives and for themselves but having a buddy to navigate complex care systems would make a significant difference.

### *Safeguarding concerns*

Families need support to understand how they can raise concerns to protect their relatives. (Everyone we spoke to would prefer to use CCTV recordings everywhere in secure units rather than have a relative secretly abused). One parent had requested the CCTV images in order to evidence a serious incident with her son in his bedroom. It would suggest that there can be no no-go areas though, as in Winterbourne abuse often took place in bathrooms and bedrooms and there would have to be a trade-off of safety versus privacy.

Two people had had investigations into abuse – one took legal action some years ago.

### Information handover

*One parent discovered that there was no Transition Policy for young people moving from children's to adult services in Southern Health NHS Trust. She had requested a copy of the policy as communication between a private hospital and their out-patient services was not effective***.**

A number of families commented on the lack of information being passed on to relatives when their loved ones are in a secure setting in adult services. The Mental Capacity Act was frequently cited as the reason why information could not be shared.

Transition is a particularly problematic time as information flow from hospital to hospital or hospital and social care can be very difficult - especially between private hospitals and NHS facilities.

*For example one parent found information was not handed over from the private secure unit to the NHS service on her son's discharge.*

### In a crisis

Families have concerns about feeling that the only backstop they have in an emergency when the situation is very difficult is to call the police. They worry about them being taken to a police station. Those who have had to do this have found the experience deeply traumatic, especially when loved ones are taken away under police escort to a secure unit.

It was not clear at times why pathways varied: some young people were placed out of county and were in or had been through residential school settings, others had been at home until a crisis occurred and then were admitted to psychiatric units, yet needs could be very similar at times.

Equally, there were people with learning disabilities who were admitted to psychiatric units because their behaviours were seen as challenging, who responded well when moved into community based settings, their behaviours improved significantly and the use of restraint was no longer necessary for some of the families interviewed.

### Lack of access to and input into care plans

Some families we interviewed had not seen their relative's care plans whilst they were in the secure unit. One person said, *"I've never seen any paperwork or a* *care plan for my daughter*". Whilst respecting that adults with capacity may choose not to have information shared with families, others without capacity need their families to know what is going on in order to be able to support them.

Some families felt excluded from the process of building assessment and treatment plans.

### *Knowing their rights of access to visit and support*

People need to understand whether they have the right to visit, to bring children under 16 onto a unit or visit a relative's room. We understand that there is nothing set down in NHS legislation that prevents under-16s visiting relatives on a secure unit. It is essential that families are given clear information about their rights of access to the unit. "The report also notes that Connor's 13-year-old brother, with whom he had shared a room all his life, had been prevented from visiting as no visitors under 18 were allowed on the ward (and he was later not even allowed in the grounds, despite it being suggested that he could). This policy exists in a number of Southern Health's mental health units" (31)

### *Lack of knowledge of the systems and processes*

There was a lack of knowledge of what the Care Programme Approach was and what the implication was for their relatives. The vast majority of families had no understanding of the Mental Capacity Act and the Mental Health Act.

### *Call for earlier intervention*

There was a strong call for early intervention and for families to receive information and training on behavioural support and person-centred approaches. ***"They don't do preventative, do they?"*** was the reaction of one carer whose son had been in a secure unit but who is now in supported living with an effective team of support workers.

Families wanted to have information about challenging behaviour and mental health needs that is offered earlier to enable them to support their relatives more effectively.

### *Care quality*

Families need to know what the characteristics of a good service should look like, but as one professional said, ***"They need to know what bad looks like too".*** Without that knowledge it is very difficult to challenge poor care. Several families spoke, for example, about the lack of interaction between the staff and their relatives on the secure units their relatives had been in.

> "The residents would be sat in the lounge, but the staff would just be on their phones and would take no interest in M"

### *Mainstream mental health v. specialist mental health services*

Some have concerns about a trend towards moving support for people with learning disabilities into mainstream mental health services because of their vulnerability. There were three parents who felt that mainstream services did not cope with supporting their relatives and it left them vulnerable. Given the number of unexplained deaths of people with learning disabilities and poor care in acute general hospitals highlighted by Mencap in their "Death By Indifference" Report, their anxieties and fears are not groundless (32)

### *Need for meaningful activities*

A number of families we spoke to had commented that their concerns about the lack of activities for their relatives whilst in the Assessment and Treatment Unit. One took their son's bike but it was never used when he was an in-patient. The use of the Mental Capacity Act and their ability to make informed choices was used as the explanation for why their relative did not have meaningful activities but they were unsure of whether they could challenge this, as they were unsure of their rights as family carers**.** They were also unsure of how mental capacity was assessed and questioned the quality of the assessments.

It is very clear that the community-based services, such as TRAX and MacIntyre No Limits were seen as very positive experiences from our studies as they provided creative, stimulating activities that brought people into closer contact with their local community.

### *Inappropriate use of restraint*

There were a worrying number of people who expressed concern about abuse or indifferent care – particularly around unexplained bruising.

Some families were concerned about inappropriate use of restraint but did not necessarily know what to do about their concerns.

## Experiences of families with higher functioning autism

Families who have relatives with higher functioning autism that we interviewed who have had very challenging behaviours, had found that that mainstream school experiences had been daunting for their children and young people.

Frequent school exclusions were a major problem as well as exclusions from school trips because of behavioural challenges.

Those that had been supported by Boundary Brook House spoke highly of the specialist support from the community psychiatric nurses in the CAMHs team.

The same themes emerged about major difficulties at key transition points in their children and young people's school careers.

It definitely felt like a cliff-edge for them, as it does for families who have relatives with similarly complex needs with learning disabilties.They also did not seem to have much awareness of the support that voluntary mental health groups like MIND could offer locally, such as access to community-based support groups and drop-in sessions.

## A model of peer to peer advocacy and support

### *Some of the elements identified*

1. Peer advocacy and support would offer support from experts by experience, i.e. family carers who had been through similar experiences, but who had received additional training to recognise the need to be sensitive to the fact that every family requires different types of support and levels of information. We would also recognise the need to work in partnership with self advocates and other advocacy services in Oxfordshire

2. Assisting in checking on quality standards by experts by experience. Frequent unannounced inspections both in Assessment and Treatment units and in community-based residential care and supported living, using experts by experience, working in partnership with self –advocates and others

3. Recognition of the boundaries of what we can do and when we need to involve professionals and signpost on to other agencies

4. Information about legislation such as the Mental Capacity Act and the Mental Health Act and the likelihood that Deprivation of Liberty Safeguarding (DOLS) will be scrapped and replaced. Similarly the new Care Bill has clear positive implications in terms of the rights of carers to a support plan (33)

5. Information about the Care Programme Approach - what it means and why it is used for some people and not others and what happens if a relative is not placed on the CPA

6. It would offer help with understanding the processes if a relative were to be admitted to an Assessment and Treatment Unit, and offer peer advocacy throughout the journey

7. It would not be time–limited but would allow people to drop back into support in a flexible way if they needed it.

8. On-line information and an online support service that is accessible at any time.

9. Written guides would also be helpful - especially for older carers.

10. It would provide peer to peer emotional support for families at a critical time

11. Support and training in how to use person-centred approaches to planning for their relative either to prevent admission in the first place, or to inform the planning process from day one of admission to eventual discharge. (One parent informed us that she believed a serious incident could have been totally avoided if the staff had read her son's person-centred plan and had understood what would trigger great anxiety in him)

12. Provision of training by experts by experience to professionals to give a family perspective

13. Independent advice on options open to their relative to avoid conflicts of interest

14. Face to face support through groups

15. Telephone texts to support people and provide information updates

16. Telephone support to provide checks on the well-being of families and to refer on and sign-post as appropriate

17. A website area dedicated to these issues / use of a secure Facebook page

18. Training on guidelines on the use of restraint

19. Knowing what good and bad services look like

20. Information about getting the environment right - including sensory issues

21. What to do when things are not working well - including complaints and raising safeguarding issues

22. Support that "didn't judge me" – a "friendly service".

23. Family carers needed very clear guidance on the rights of their relatives both under 18 and over 18 years of age and also to know what their rights were are family carers

24. Families need information and support around assessment of communication

25. What Positive Behavioural Support is and how to use it at home (34)

26. Information about medication and side–effects and alternative treatments

We would recommend that these issues are explored and scoped in more detail with potential partners to define much more tightly the outcomes and outputs of such a service

“ I don’t walk to talk to anyone when I am in my deepest, darkest place but the experience of being able to use on-line support at those times would ease the pressure.  I don’t know anyone who has a bi-polar relative with a learning disability”. Comment of a parent.

# Key Recommendations

## Developing alternative models of care

Families want help to develop alternative models of care and support. Family carers who are unfamiliar with person-centred planning, need information and training to understand how person-centred thinking works. This will equip them to design support for their relative that enables them to have a fulfilling life (Appendix 3)

## A peer to peer support service

- A pilot peer to peer support network is set up, using trained experts by experience, to ensure that families are supported and given the information they need about their rights and responsibilities for their relatives

- Families recognise that in a crisis they would need professional support but would also welcome peer support at that point and more importantly along the whole journey through assessment and treatment, including support in reviews.
  ***This is not a replacement for statutory support but a vital addition to support for families***

## Action plan for Oxfordshire Family Support Network

As a result of the work we have been doing with the families we have interviewed, we now have a clearer idea of the model we need to develop but we recognise it neeeds further testing and development.

We have held an initial development meeting where we discussed our proposal and a steering group has now been set up with national organisations to develop further the scoping of the proposal. We recognise that we are working *locally* on issues of *national* importance that affect many lives.

| Action | Timescale |
|---|---|
| Publish Oxfordshire Healthwatch Report for discussion | April 2014 |
| Identify partners and funding for further more detailed scoping | April - June 2014 |
| Development of a pilot to test out peer advocacy model for families in Oxfordshire | September 2014 - September 2015 |
| Work on sustainable funding if pilot successful to obtain 3 year funding | January 2015 onwards |

## Transition planning

1. **The lack of a Transition policy in Southern Health NHS Trust needs to be urgently addressed** and appropriate policy guidance needs to be developed to accompany this

2. We suggest that the Winterbourne Concordat group work together with families to develop a clear policy locally about transition and that a transition pathway covering the specialist needs of these young people is developed

3. Health Services need to develop transition nurse specialists in Oxfordshire who can support families who have relatives with Learning Disabilities, Challenging Behaviour and Mental Health Needs through transition from children’s to adult services so that they are informed of the processes. These nurses would work with both health, education and social care agencies

4. All young people coming into Mental Health services at 18 with these complex needs should automatically be put on a CPA until their needs are fully assessed and support services are put in place. Their families need information about what a CPA is and should be informed about how they can be involved

5. We recommend that as the single assessment plans, covering Education, Health and Social Care are introduced for every child with Special Educational Needs and Disabilities, under the SEND reforms, they are used as an opportunity to aid early identification of children and young people who have behaviours that challenge (35)

6. The single assessment plans should have clear timescales for delivery of support to families. These plans should use person-centred approaches and positive behavioural support plans should be put in place that are implemented and monitored regularly. A pro-active approach will be better able to pick up earlier, children who may otherwise develop much more severe problems. We know that there has been really positive co-production on the Local Offer for Information and we would like to see this built upon for children and young people with these complex needs (35)

7. As a start, in Year 9, we would like to see that every young person with SEN and disabilities have an assessment of their mental health needs, their sensory and communication needs. We recommend that there is a detailed behavioural support plan put in place for any young person who has behaviours that challenge, that is acted upon and is updated regularly as they move into adult services

8. Schools can play a key part in early identification of young people who may be at risk of developing mental illnesses. However, families we have spoken to feel that they need better training and awareness. Professionals and experts by experience can all contribute to this training

9. Every parent of a person with learning disabilities should be given the opportunity to understand the workings of the Mental Capacity Act and Best Interests meetings from year 9

10. Information transfer should be handed over from in-patients to community-based services and needs to be shared across health and social care agencies to ensure smooth and safe transitions

11. Create effective IT systems that share information between Health and Social care. This is vital and potentially could save lives and family crises

12. All young people who have been in secure units under the age of 18 should automatically be placed on a CPA in adult services until everyone is confident that there is a clear handover and transition plan in place that works well to ensure a smooth flow of information and support

## Safeguarding

1. Information about the safeguarding process must be clearly displayed on all units and must be given to parent carers of people with learning disabilities who use mental health services, irrespective of the mental capacity of relatives

2. Families require really clear information about Mental Capacity and Best Interests. They also need to be given information about the Mental Health Act and the current Deprivation of Liberty Safeguarding (DOLS). As it has now been proposed that the DOLS safeguarding should be scrapped, this will mean that there will be more changes pending that need to be understood

3. Family carers need to have very clear guidance on the rights of their relatives both under 18 and over 18 years of age and also to know what their rights are as family carers

4. Families need support to understand how they can raise concerns to protect their relatives. Everyone we spoke to would prefer to use CCTV recordings everywhere in secure units rather than have a relative secretly abused

## Access to support in crisis

1. Families need to know where they can go to “get into the system”. People are clear that they want one point of contact from professionals to know where to go to get information, advice and support when their relatives are unwell or their behaviours are seen as very challenging. They need to be able to get quickly to support without being handed around from one agency to another, particularly out of office hours

2. The need for a safe place that is not a police cell. As we have highlighted in the barriers / solutions exercise, we recommend that there is a safe, secure and less threatening place that people are taken to and that consideration is given to taking time to reach a solution. This is crucially important for young people under the age of 25

3. ***We strongly recommend that there is an in-patient facility that is adolescent-friendly, developed for young people with learning disabilities under the age of 25. Currently any young person with these needs has to go out of county***

## Development of market for self-directed support

Families were not sure about whether Personal Health Budgets would be easily available to their relatives, nor did they understand the process of getting one. Locally, voluntary sector providers, and the user led organisation, Oxfordshire Wheel and other user-led organisations such as Community Glue need to be working in partnership with NHS England and statutory agencies to provide support to families to use personal health budgets and develop personalised solutions which have been shown to be effective elsewhere.

## Understanding Processes

The Royal College of Psychiatrists has a checklist available on their website for relatives who are admitted to hospital to help them to understand what should happen when their relative is admitted as in in-patient and for when they attend reviews. This should be given to all families, as should information on the CPA (36)

## Understanding care quality

Families need to know what the characteristics of a good service should look like and indeed should be involved in the development of care quality guidelines locally.

The Government report "No Health Without Mental Health" (37) - a cross-government mental health outcomes strategy for people of all ages comments:

*"4.20 Families and carers, young and old, often receive limited help and too often report that they are ignored by health professionals on grounds that they need to protect the confidentiality, and respect the wishes, of the service user. However, families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered"*

This is a helpful approach for all families, including families who have relatives with learning disabilities, autism and challenging behaviours or mental health needs and needs to be embedded in local practice.

## Using the Health Equalities Framework

Families need support to check if there are health inequalities for their loved ones that need monitoring and tracking over time to ensure that health inequalities for their specialist needs are being addressed.

The Health Equalities Framework gives a useful tool that can be used by family carers and people with learning disabilities to track what is happening locally over time. It may be a useful exercise to develop this in Oxfordshire. It may need further development as a tool to ensure it identifies health inequalities more specifically for this group of mental health service users (38)

There is also another useful resource, The Green Light Toolkit (a guide to auditing and improving your mental health services so that it is effective in supporting people with autism and people with learning disabilities) (39).

We recommend that these tool kits are used by experts by experience and professionals working together.

## Skilling up the work force

There must be more local investment in training for staff in schools, respite care facilities, in-patient and community based services in order to ensure that people with behaviours that challenge can be safely supported.

By developing a significant pool of highly skilled staff, it is much more likely that people with challenging behaviours and mental health needs can be supported in community based services

We need to build capacity to ensure that children and adults with challenging behaviours can be supported within respite care provision.

As Professor Mansell observed "A particular problem for people with learning disabilities who present challenges is that, although their needs for a short break may be very high, local authorities may discriminate against them because traditional local respite services find it hard to provide the support required. They may therefore be excluded from short breaks". This was certainly the experience of some of the families in our study (11)

## The use of Positive Behavioural Support

British Institute of Learning Disability (BILD) guidelines on Positive Behavioural Support (34) recommend:

"Primarily, organisations should develop models of support that focus on the prevention of socially invalid behaviour rather than the management of such behaviour.

This can be done through:

1. Improving skills within the workforce and delivering focussed training
2. Developing appropriate policies to support a framework for service delivery
3. Developing and supporting an appropriate culture and ethos which places people at the centre of their care
4. Improving communication and access to interpreters and accessible information
5. Emphasising good practice and sharing good practice across services
6. Focussing on peoples individual needs and ensuring these can be met
7. Offering appropriate support to employees
8. Delivering care within a framework that acknowledges and protects people's human rights"

# Training GPs

Families we spoke to wanted to turn to their GPs whom they saw as providing trusted support but they recognised that they often did not have the detailed expertise around their relatives' complex needs.

The Lords Select committee (15) recommended that there was better training on the Mental Capacity Act in all post-graduate education - especially for GPs. This is clearly something that the new Oxfordshire Clinical Commissioning Group (40) can address.

# Commissioning

Geographical boundaries that are not co-terminus between health and social care in Oxfordshire were highlighted in this report. Families need to know that there can now be flexibility for commissioners to purchase services across boundaries.

The Lords Select Committee on the Mental Capacity Act also recommend in their report:

***"That local commissioners work with families and with people with learning disabilities to both inform families about the commissioning process and to enable families to play a part in shaping what the services should do"***

"*Commissioning has a vital role to play in ensuring that the Act is implemented and complied with in practice. We have noted examples of how commissioners can promote good practice through support and contractual requirements. We recommend that the Government, and subsequently the independent oversight body, work with the Association of Directors of Adult Social Services and NHS England to encourage wider use of commissioning as a tool for ensuring compliance*" (15)

Families expressed real concern about how such poor quality services could be commissioned locally in Oxford and feel very let down by the weaknesses that were very evident when the CQC visited and carried out their unannounced inspection that led to the closure of STATT in Oxford.

Such failures require commissioners to have a close working relationship with providers so that there are "no surprises". They should know how these services are performing with robust performance indicators that measure things that really matter and are manageable for staff to maximise time is spent on patient care and in providing personalised support.

These performance indicators could be developed in partnership with families and people with learning disabilities and monitored for positive outcomes.

Jenny Morris writing recently in her blog (41) talks about the importance of the principles of open contracting where local communities are informed and empowered to play a part in the commissioning process. Two of the key principles are:

- *"Governments shall recognize the right of the public to access information related to the formation, award, execution, performance, and completion of public contracts"*
- *"Governments shall recognize the right of the public to participate in the oversight of the formation, award, execution, performance, and completion of public contracts"* (42)

We strongly recommend that families who are experts by experience are given training, information and support to effectively participate in such open contracting locally for these services, as public confidence in the commissioning process for these specialist in-patient services has been severely damaged.

We note the approach that Plymouth have taken in making a leap of faith to provide services differently through the Beyond Limits project. (Appendix 2)

## The need for local accountability

Increasingly, we are seeing two opposite forces at work on services, as funding constraints lead to more and more bodies combining forces to create economies of scale within services. This is particularly true in the NHS where only the large Foundation Trusts are surviving. We have lost much of the local accountability from organisations because specialist mental health learning disability services are now part of a much larger organisation, Southern Health NHS Trust, that crosses a number of local authority boundaries. Strong local accountability needs to be re-introduced.

The latest findings from the Winterbourne Joint Improvement Programme, on the lack of progress on the movement of people out of secure units, though deeply disappointing, demonstrate the need for information to be gathered to create pressure for change.

This data needs to be very much in the public domain and should be readily available to all families who use Assessment and Treatment Units. We share Bill Mumford's view that this data now makes it possible to hold local commissioners and service providers to account and to monitor progress towards better support for this extremely vulnerable group of people. This data needs to be readily available to the public on Health and Social Care websites and also needs to be regularly reviewed by local Health and Wellbeing Boards.

Bill Mumford states "Transparency is extremely important as a catalyst for change and as information sharing improves it will become increasing apparent where work is needed and where support should be targeted. In addition the legacy of ongoing data collection will continue in a way that will maintain local scrutiny by stakeholders beyond the length of this programme."

# Conclusion

This qualitative research report is designed to give an overview of the information, advice and support needs of families who support relatives with learning disabilities having highly complex needs.

We recognise that at times, professionals and families are stretched to the limits to support this group of people but we strongly believe that by using the knowledge of experts by experience who are family carers, we can work together to improve the lives of these particularly vulnerable people.

We need to establish a fundamental principle that experts by experience – who are either family carers or people with learning disabilities - should work with local specialist mental health services in the community and in in-patient facilities to improve the lives of people who use these services. The barriers between families and professionals have to be removed. Family-friendly ways of working are being developed in acute general services and we need to ensure that mental health services do the same.

We want to ensure these services are strongly locally accountable to the Local Learning Disability Partnership Board, and to local bodies, such as the Health and Well-Being Board and local Healthwatch, in order to safeguard people with learning disabilities.

We are deeply concerned that there is no local in-patient facility for young people with learning disabilities who are under 25. In acute general hospital services, adolescent units have been created in a number of specialisms. The needs of young people with learning disabilities, who have mental health needs and challenging behaviours requires the same focus for those who require assessment and treatment. They should not have to travel to locations like Norfolk, far from their families.

However, the fact remains that the local assessment and treatment unit failed the CQC inspection - geography alone does not make a service safe. We have to work together, so that families are well-informed and play an active part in supporting and safeguarding relatives locally.

In particular, we have concerns about the use of restraint. We support the comments in the Government Report, "Closing the Gap" that calls for changes in practice around the use of restraint (44)

Families can only play an effective role in safeguarding if they are well-informed about the rights of their relatives and their rights as carers. The families we spoke to felt that a peer to peer advocacy service could be a very valuable additional support and we are keen to scope this out more fully.

We call for specialist mental health services to work with families to address the barriers that have been put in place regarding the use of the Mental Capacity Act. We are heartened that nationally, the House of Lords Select Committee are recommending radical changes to the use of Deprivation of Liberty Safeguarding. We want to see local protocols for working with families to share information, and to actively and appropriately involve them in assessment treatment and discharge planning, in line with the National Mental Health Strategy.

We are encouraged that the latest Government Report, "Closing the Gap" identifies 25 priorities for change that closely reflect issues raised by the families who participated in our research.

Agencies need to work with families to deliver support in radically different ways. There are local people who can attest to the fact that delivering support in a person-centred way, can truly transform lives. We are seeing evidence of this in the work nationally of projects such as Beyond Limits in Plymouth whose commissioners backed working in a different way (Appendix 2). The Challenging Behaviour Foundation Everybody Matters campaign have fine examples of individual lives being by transformed. These services are characterised by providing personalised, high quality, well-trained support in the local community. People with learning disabilities are being re-connected to their communities by this inspiring work (45)

We need to urgently fix a broken system locally by using the energies and creativity of families and professionals working together, starting from a blank sheet of paper to create a service that is radically different. We need to ask, "Is this good enough for our sons and daughters?" "How would we want our family to be supported if we faced these massive challenges?"

### Families need information in order to achieve transformation

We feel the final word should go to Dr Sara Ryan…

## Extract from Connor's Manifesto

***For all the young dudes:***

- A change in the law so that every unexpected death in a 'secure' (loose definition) or locked unit automatically is investigated independently
- Inspection/regulation: It shouldn't take catastrophic events to bring appalling professional behaviour to light. There is something about the "hiddenness" of terrible practices that happen in full view of health and social care professionals. Both Winterbourne and STATT had external professionals in and out. LB died and a team were instantly sent in to investigate and yet nothing amiss was noticed. Improved CQC inspections could help to change this, but a critical lens is needed to examine what '(un)acceptable' practice looks like for dudes like LB
- Prevention of the misuse/appropriation of the mental capacity act as a tool to distance families and isolate young dudes
- An effective demonstration by the NHS to making provision for learning disabled people a complete and integral part of the health and care services provided rather than add on, ad hoc and (easily ignored) specialist provision
- Proper informed debate about the status of learning disabled adults as full citizens in the UK, involving and led by learning disabled people and their families, and what this means in terms of service provision in the widest sense and the visibility of this group as part of 'mainstream' society

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# Appendices

## Appendix 1

### Topic Guide questions for the research

#### The context

What were the circumstances that led to your relative experiencing mental health issues or behaviours that challenged?

What is the age of your relative?

#### What worked and did not work

What worked well in your experience about the mental health services for your relative when they were experiencing mental ill health?

What worked well for you as a family carer throughout that time?

What did not work for your relative and for yourself about using mental health services?

#### Information

What information, advice and support was offered to your relative throughout the assessment and treatment offered?

What information, advice and support was offered to you as a family carer at the time?

Looking back, what information, advice and support would have been helpful to have right from the start?

#### Rights

What information were you given about the legal rights that your relative had whilst undergoing assessment and treatment?

What information were you given about your rights as a family carer?

Did you know if your relative was sectioned or not? Did anyone explain what section of the Mental Health Act they were held under, if relevant and what it meant for you and your relative?

Did you know anything about the Mental Capacity Act and about Deprivation of Liberty Safeguarding when you relative was using mental health services?

What choices were offered to your relative about activities and routines of daily living whilst being treated?

## Quality and safety of experiences

How well were staff trained in your view?

Can you give an example of good support?

Was there any support that was not working for you?

What was your experience of the planning of the discharge process if your relative was an in-patient?

How did the staff involve you in your relative’s assessment, treatment and subsequent discharge?

How safe was the environment that your relative was treated in?

Who would you have gone to if you had any concerns about your relative’s wellbeing or safety?

How well did the various placements and support meet your relative’s needs?

## Improving services

Was there anything that could have been done differently, in your experience, that would have led to better outcomes for your relative?

Was there anything that could have been done differently that would have made the experience better for you?

Do you feel that a support group to meet others or one to one support from a parent who had gone through similar experiences would help?

What other help do you think families need to get good support?

Is there anything else you would like to tell me about your experiences that would help us to understand the information and support needs of families?

# Appendix 2

## What is person-centred planning?

‘The purpose of person-centred planning is to inform action that makes life better for people with disabilities and the people who know and love them.’

John O’ Brien and Connie Lyle O’Brien (co-developers of person-centred planning)

The Helen Sanderson Associates website has many examples of person-centred planning:

http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning.aspx

## Useful resources

Personalisation through Person-Centred Planning:

http://www.helensandersonassociates.co.uk/media/11242/personalisation-through-person-centred-planning.pdf

Use of person–centred planning for people with mental health needs:

http://www.helensandersonassociates.co.uk/reading-room/who-/people-with-mental-health-issues.aspx

Person Centred Thinking Tools:

http://www.thinkandplan.com/

For people who have not had person-centred planning training:

http://www.thinkaboutyourlife.org/

# Appendix 3

Case study of Beyond Limits information taken from #107 Days website

*"I and Doreen Kelly set up Beyond Limits nearly three years ago in conjunction with the then Plymouth PCT (now NEW Devon CCG) to set up what I now come to realise was an inspiration project to plan with the 20 people with learning disabilities and their families who had been cruelly placed in Assessment and Treatment Units across the UK, to bring them home where they wanted to be. Inspirational because the commissioners were taking a leap of faith, admitting they had got things wrong and would work in real partnership with us as a Provider, and families and people, for probably one of the first times.*

*Beyond Limits will work with each person as an individual - one person at a time.*

We won't provide group support unless people with learning difficulties or mental health issues ask for it. But this is unlikely. We think group services often cause 'challenging behaviour'.

**Careful planning**

The support we provide is based on careful planning. There is an overall Service Design that sets out how we will support someone using paid and unpaid support.

**The Service Design** is worked out in planning meetings with the person, people close to them and professionals. The person must agree who is at the meeting. The meeting considers where the person will live, who will support them, how they will spend their time and how they will find their place in the community.

There is also a **Working Policy** which has a plan for how to respond in difficult times when, for example, the person's behaviour tells us we've got something wrong.

**Citizens not clients"**