National Development Team for inclusion

Informing the Service Model

A report about the experiences of people with learning disabilities and families

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for Inclusion

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Introduction

NHS England (NHSE), the Local Government Association and the Department of Health are developing a 'service model' for people with a learning disability and/or autism who have a mental health condition or whose behaviour challenges. The service model will set out what good health and social care services look like.

The draft service model is being developed with the help of a reference group including people with learning disabilities, families, clinicians, commissioners, academic experts and others. To inform the development of the service model, NHSE asked the NDTi to run focus groups for people with learning disabilities and families who have experience of in-patient services in each of the four regions. This report summarises what NDTi did, and what people told us.

We would particularly like to thank the Challenging Behaviour Foundation and Mencap for enabling us to attend the meeting they had arranged with families on the 26th June.

Who we talked to

People with learning disabilities

We worked with self-advocacy groups in each of the four regions to co-host focus groups. The self-advocacy groups also helped us find people with the relevant experience. We are very grateful for their help with this project. The details of who we worked with are as follows:

NHS East and Midlands 15th June in Birmingham with SpeakEasy N.O.W. Six people with learning disabilities and four supporters from four organisations attended. Several members of this group had personal experience of in-patient services, and one had helped to produce a report on “Locked Hospitals” in their Region. See: www.speakeasynow.org.uk/images/health_checkers/locked_hospital_report.pdf

NHS South 16th of June in Oxfordshire with My Life My Choice (MLMC). Seven members from MLMC and one supporter attended. Several members of this group had personal experience of in-patient services, and also of being Experts by Experience (ExEs) on the recent round of NHS England South Care and Treatment Reviews (CTRs).

NHS London 23rd June with Safety Net People First and Hammersmith and Fulham Mencap. We also contacted Advocacy in Greenwich, who helped us contact people. There were seven people with learning disabilities at the meeting, four of whom had experience of being Sectioned, and four supporters from five organisations.

NHS North 9th July in Newcastle with Skills for People. There were three people with learning disabilities and three supporters from three organisations. One member of this group had (a bad) personal experience of in-patient services. One had been on several CTRs and one had been involved in a programme of staff training for the local NHS Foundation Trust.

Families

It proved to be easier to engage with some families through telephone interviews. We are grateful to Inclusion East and the North West Training and Development Team for helping us connect with these families. In total there were eleven telephone interviews with family carers.

We ran a focus group meeting in Oxford in partnership with the Oxfordshire Family Support Network (OxFSN) on the 25th June. Six families attended.

We also attended a meeting arranged by the Challenging Behaviour Foundation and Mencap on the 26th June where the service model was being discussed with representatives from NHS England, the Department of Health, the Local Government Association, the Care Quality Commission and ADASS. Ten family carers attended.

One family member who couldn't attend sent in a response on the questionnaire format we provided (see appendix I for the questionnaire format).

We were able to record information from families in different way from the information gathered from people with learning disabilities, therefore there are some differences in the following two sections, although there are many common themes.

What people told us

People with learning disabilities

Key themes from the focus groups have been summarised below and have been illustrated with direct quotes from the participants. People with learning disabilities didn't talk about what happened before they went into hospital.

In-Patient/ATU Services

What worked well

- I went in "to get better in the head" and was helped by being helped to talk about it, on my own and in a group. Also by doing art work.
- In the high secure unit, college tutors came in to run sessions.
- "You could cook a meal for everyone in the mother and baby unit which was good".
- "I know I was safe in the unit. I asked how long I'd be there and they told me"
- It's good to have a familiar routine so that you feel comfortable and know what to expect.
- It's good to be able to keep in touch with home.
- When members of the self-advocacy group came in to meet the people there "They talked to us more than the staff".

What didn't work well

Communication between staff and the individual patient in Assessment & Treatment Units (ATUs) needs to improve a lot.

- "Help them to understand it more" in their own way, as the people inside these units cover a wide spectrum and not everyone can grasp the meaning of words.

- “I don’t like big words or doctor words”
- “They didn’t explain to me about what section I was on. It felt like being in prison.
- When I was in hospital I didn’t understand why I was in there. They could have explained it in Easy Read, big print, no jargon, pictures etc”.
- “They told me that my Hospital Passport was no good to me there”.
- “Information wasn’t given in a way that was easier to understand. I find pictures and big words helpful and having someone to explain it and go through it with you. It’s about having dedicated time. Not being rushed, having protected time”.
- “A Doctor said to me, ‘I’m a professional I know what’s best’. I just wanted to go home. She didn’t have no professional manner. She treated me like a piece of poo really”
- “It helps if staff tell you how long you have to be there. After 4 months they suddenly told me I was leaving, just a week before I had to leave”.
- “Staff should talk to me, not beat me up”
- I had my dignity taken away. They didn’t treat me with respect”

Often, hospitals have very little or no communication with families that want it (and not just because they live a long distance away). Also, the places where family visits take place could be arranged differently.

- “It’s just a little room. It would be better if you could go to a café on site”

The medical notes sometimes feature out of date statements that haven’t been updated e.g. “when she first came in” or they are missing key (relevant & current) information. Historical labels stick to people e.g. the statement of why they came into hospital 12 years ago is still prominently placed in their notes. PLUS the notes don’t give you a full sense of the actual person they are describing. The choice of words used by in patient health service professionals can tend to be negative and dismissive of the person e.g. referring to someone as a “lost case”. Note – these points were made by people who had been involved in CTRs

Having the opportunities to do classes or sessions doesn’t always follow people through the system (high secure/low secure/step down) which means that people miss out on the chance to keep developing skills and confidence that would benefit them “on the outside”.

People were not included in meetings:

- “I was in music therapy and people were talking about me when I wasn’t in the room, and then when I was in the room they ignored me, treated me like I was invisible, and wouldn’t let me speak”.
- ‘It can make you more annoyed inside. If people were calm with you and included you, you probably would have felt a bit better”.

Having an advocate can be very helpful:

- “My advocate spoke for me after I told her what I wanted to say. I didn’t have the courage to speak myself (in the Review meeting)”
- “The advocacy service helped me get a solicitor (who challenged my Section).

BUT not all advocates are created equal;

- Members of community based self-advocacy groups are used to being engaged with, listened to and supported in a constructive way.
- In hospitals, advocates can come across (to the patient) more like just another member of the group of medical professionals in charge.
- “It should be explained to them better what advocacy is. One person there had declined an advocate, but after we spoke to them (at the CTR) they asked for one”

Some people have got stuck in the system e.g. those who are still there under a (historical) Ministry of Justice order.

- “People being sent into units, they should assess them more frequently to see how they’ve got better, and if they can go back out into the community with support so that they don’t relapse”.
- “People need to have a plan for when they are released from hospitals”

What needs to be in place

It is vital that there are regular opportunities for outside **“eyes and ears”** to go into in-patient settings, and ask questions that challenge the prevailing (medically based) approach to assessment & treatment, and underline the value of adopting person centred ways of working.

The Experts by Experience who took part in the Focus Groups want to be **better included**

in the whole CTR process (including receiving copies of the final report on their visit “to make sure our voices have been heard”).

Self-advocacy groups potentially have an important role to play:

- They can train in-patient services staff by challenging (limiting) attitudes that assume that people cannot manage to live out in the community and will not be able to achieve new goals.

Coming home/ back into the Community

What worked well

There was a story about the good links between the Hospital Staff Team, the Community Team, the person and their family which showed how someone could be supported to have a very different life after many years “inside”.

“Going out places. Meeting new people. Going to Drama Group (which started in the hospital & includes people still living there as well as people who are now out in the community). Everyone makes up a story (based on their own experiences)”.

- “My care coordinator is like a support planner”.

What didn’t work well

There doesn’t always seem to be coherent, consistent communication locally between the various organisations and individuals that could help support people’s “re-entry” better (and in some areas the established links and resources are being removed so that the people who have the history and who know what’s going on and how to access it, will no longer be there).

What needs to be in place

The need for **good support (“the right kind for me”)** managing day to day living, connecting up with local people and places – “to prevent me from going back into hospital”. It helps to ask the question “why?” about someone’s behaviour.

“Employ decent staff”

Staff who understand about not overloading people – creating stress and anxiety:

- “When you get too much information on your brain”

“Prescriptions aren’t in **Easy Read** telling you about the side effects. There should be pictures on it and on the packaging”

This includes support to attend hospital “Then they offered outpatient after being there for a bit. I didn’t like it, they were very rude, but my family made sure I went back every day. After a period of time I didn’t have to go, but I didn’t have a supporter for going to hospital, so my family had to go with me from 8am to 8pm “

“Social Services now only pay for your welfare, not for your activities, even though they help to keep you occupied, they help to get you out and about. But without those **activities**, you end up back in the hospital”

Self-advocacy groups potentially have an important role to play:

- They can offer friendship/support to the individual from people who may well have had similar experiences.

“I think that when people hopefully come out of hospital that they get **the right sort of budgets**. The people who have been locked away should be able to choose who is in their team, be spoken to in a way that is respectful and in a way that they understand”

People with learning disabilities value **seeing and experiencing “Progress”** in their lives where it is clear that they are being well supported to develop their own skills and the self-confidence to take more decisions for themselves. In this context, Commissioners could include performance indicators in contracts to show how well support providers enable people to **make friends and develop relationships.**

While it is very important that the authorities make information available in Easy Read wherever possible, they also need to ensure that there is **someone to explain the materials** to the person concerned.

Family carers

Staying well, staying safe in the community

What worked well

The only things families mentioned that worked well was support from external agencies such as the Challenging Behaviour Foundation and for one family a community care lawyer (who was able to provide advice on the use of the Mental Capacity Act).

What didn’t work

People were not adequately assessed, and as a result there was no understanding of the person’s behaviours. Professionals did not listen to families or value the important perspectives that they bring to understanding the child/person and what effective support looks like for them as an individual. This resulted in escalating challenging behaviour that should have been understood and managed better. This lack of understanding was very distressing for the child/person and their family. It took too long for professionals to accept families perspectives – *‘I am the project manager for all his support. I am the one working* *to get the professionals to talk each other'.*

There was a fundamental issue around the culture of professionals within these services – too often families are actually perceived to be the problem, rather than an integral part of the solution.

There was a lack of skilled and timely support on offer to stop difficult situations escalating and the young person/ child or adult being admitted into inpatient provision. Many families had been through this experience and the child/person had been admitted to a service out of their community and for some that provision was many miles away. Transition planning is poor. There is a failure to communicate between child and adult services. For example, one family reported that no adult social worker was allocated and the young person was not known to the health learning disability team. In one case, there was a failure to communicate with the young person regarding a change of school so he was unable to say goodbye or adjust.

Services and schools promised things they couldn't provide. The use of agency staff is very detrimental. Families are not given information on what is available – including advice on use of a direct payment.

There is a lack of local bed based provision, and a lack of timely and effective crisis intervention support services.

The crisis was precipitated by the lack of skills and knowledge of the people around him. This includes - diagnostic overshadowing – they don't always see the mental health issues assume the behaviour is because the person has a learning disability. It took us a long time to get his mental health needs recognised.

There is too much reliance on the use of medication –*' The medication they gave him was enough to knock out an elephant'.*

Everything took so long - *endless meetings of agencies discussing the methodology which delays timely action and joint working*.

There is a lack of choice for families regarding the services they can access through social services. Personal budgets and personal health budgets should be much easier for families to access.

What needs to be in place

There needs to be more **person centred care and support**. There is a lack of person centred support services in both the community and ATU/ inpatient provision. Those families that have managed to achieve person centred support for their family members have done so because they have been proactive, determined and well resourced. One family bought the house their son now lives in. Another had to do all the work to find a local provider and Housing Association for his accommodation in order for him to be discharged. Services should facilitate the use of personal budgets and personal health budgets

There needs to be **proper understanding and use of MCA Best Interest meetings** by social workers – who should not be allowed to use them perversely and unlawfully. DoLS need to be much clearer with less jargon and paperwork. Information needs to be shared between counties.

There needs to be more **preventative care and support services** in the community. There is a lack of joined up preventative services in the community. Families described how there was not the support available when they needed it. It was hard to get information on how to get help and even if you found out, hard to access it.

There needs to be **intensive 'crisis intervention' support services in the locality**. There is a lack of joined up 'crisis intervention' services for intense support to work with the person, their family and support workers to stop admission and keep people safe and well in the community.

Support providers who can provide good quality support to people in the community. There is a lack of choice for people with complex needs to provide the person centred care they require to stay safe and well in the community, and a lack of small local provision.

A provider workforce that has the right values, skills and knowledge to support people safely and well in community settings and their own home. All the families emphasised the real problems they experienced because of unskilled and often under-valued front line workers. Families recognise that these workers are crucial in managing the day to day wellbeing of their family member. Without the right skills, knowledge and values these staff can precipitate a crisis by escalating behaviour that is then deemed so challenging that the person is sectioned or excluded. There are also huge issues with the use of agency staff – lack of continuity and consistency, which also generates problems.

Specialist practitioners in the community who can provide support to the person, family and front line support staff in an accessible and on-going way. Families talk about the problems in getting the support from a range of practitioners and how this can mean an over reliance on medication. They have experienced difficulties in accessing support from CAMHS, Speech and Language and OT, as well as social workers and psychologists. Often the waiting lists are over a year long.

There needs to be much better **communication between child and adult services and robust transition planning.**

There needs to be **recognition that it is *very harsh treatment*** *to send a vulnerable person away to hospital…away from their friends and family at a time when they need* *support more than ever.*

There needs to be better **CQC inspections** to prevent abuse.

Inpatient /ATU experience

What worked

There were a few examples of things that had gone well in ATUs, often after things had initially gone wrong.

A good multi-disciplinary team who are knowledgeable about PBS, are well managed and avoided using medication is crucial. Also teams that did not use restraint. It is important for teams to *'stick with the person'*. These teams listened to family and other people close to the individual. Being in a place that was relatively local, so that the environment was familiar, is important.

The use of graphs in hospital to understand one man's challenging behaviour and a diagnosis of severe auditory processing. The family were then able to feed the diagnosis back to the social worker, who had ignored this issue previously.

Families mentioned a number of individuals/services who had intervened to improve things:

- The psychologist from the Tizard centre who understood and knew about PBS
- The right solicitor
- Seeing a consultant psychiatrist who understood
- The independent reviewing officer who got that it was wrong and had the clout to do something about it.
- Norman Lamb
- PCP and the Improving lives review
- Social services realising there were safeguarding concerns

The Challenging Behaviour Foundation was regularly mentioned as being particularly supportive for the group of families associated with it. Other families in the telephone survey had not heard to the CBF and said they wish they had.

What didn't work

The use of Mental Health Act sections is a cause of concern. One family commented that it seemed to overrule direction of policy to keep people in their own community. - *We* *asked CAMHS for help and he ended up being sectioned. He was excluded from school – they said they couldn't cope so he'll have to come home to you. But there was no support for us on offer though*. Another family were concerned that section two rather than section three (with 117 aftercare) was used, and the follow up by the psychiatrist and the MLDT (with no input from the social worker) was not useful. It was also thought to be too easy to renew section 3 without listening to the parents' voice. Once someone was admitted to an assessment unit, there should be an agreed time frame, and a written agreement with parents. There was confusion about Community Treatment Orders, and what they meant. There are concerns about the skills and knowledge of professionals involved in the sectioning process itself.

Families reported that the needs of people with autism are not understood or taken into account, leading to admission to units that do not meet people's needs. Doctors are not held accountable when people deteriorate in in-patient units, although they are responsible for putting them there. When children are damaged in acute hospitals there is compensation – but families don't get compensation when their children are damaged in assessment and treatment units.

Families were almost unanimous in their condemnation of the experience of their relatives' health in inpatient provision. For one young man, the anxiety caused by the placement led to behaviours that had a detrimental and permanent effect on his health.

Families are particularly critical of the lack of person centred care and support and the group ethos that prevailed. There is huge concern at the lack of person centred activities on offer. There was also a concern that their family member had become 'institutionalised' and had lost key skills. For example the lack of opportunity to make a cup of tea or be involved in developing skills for independent living. As well as losing skills, people developed further challenging behaviour, and were traumatised by the experience of being in in-patient services – as were their families. Because behaviour had deteriorated, it was harder to find suitable community placements. One family were told the admission was for 28 days but it went on for 15 months. During this time they were sent to different places that would have been suitable prior to admission, but no longer were.

Families reported that nothing happens in ATUs. '*There is no effective intervention- staff record their observations every 15 minutes but they don't interact and, it is the interactions that should be recorded.*'One family member talked about the '*sheer boredom'* her son experienced. The skills and knowledge of day to day staff is crucial but they are a devalued and often an unskilled and under supported group themselves. '*They do not seem to be implementing a Positive Behavioural Support approach. There is no focus on learning. These environments are not therapeutic; they are making things worse and yet are so expensive.'*

We have an excellent care package to keep him out of hospital - I hold the Personal Budget and we have a team of great PA's. Sometimes we need the ATU as a way bringing him down during a manic stage. His PA's go into the unit to support him and ensure he is doing stuff which is good because the ATU not doing much with him - a holding job.

Families reported a lack of liaison with the Community team. His assessment is taking forever, and there is no discernible link between staff within the unit either, which means a delay in establishing treatment. This includes the blood tests linked to trying him on new medication let alone psychological treatment. Inadequate assessment of need led to inadequate support. Social services tended to disappear when people were admitted.

Use of restraint and seclusion is both extremely distressing and counterproductive –' the more they restricted the more he challenged'. Restrictive practices such as locking the bathroom door when a young man wet his bedlinen had created long lasting anxiety, as the bathroom was the person's place of safety. Families also reported that access to their family members had been restricted.

Families felt that there was excessive use of anti-psychotic medication with associated distressing and debilitating side effects.

Families reported that their family members had experienced assaults, but in one case the safeguarding meeting was held months later. At the meeting the nurse said it was person's own fault as they didn't get out of the way quickly enough. There was no liaison between safeguarding officers. Another family said that a change of management had resulted in a more institutional model and abusive practices. Families felt that there was a failure to address issues raised, and very poor practice. Examples included giving incorrect information to the police and failure to send items that were important to the individual with them to a new placement. 'It is torture to watch your son in the hands of 'experts', and you can't do anything about it'.

There were many examples of procedures and systems not working. These included safeguarding, complaints, tribunals, MHA manager meetings, Care Programme Approach meetings (treated as a tick box exercise), CQC inspections and advocates that were 'in house'. There may be a perverse incentive for private providers not to discharge.

Families reported that they are not listened to, communicated with or involved in decision making processes. Families also feel that they and their family member were blamed for the situation. There was no accountability. One family tried to contact a commissioner, but the area commissioner didn't see a problem and the local one had no jurisdiction.

Placements were often remote, making it very hard to visit, and there was no interaction with the community. It was difficult to communicate with family members in these units. There should be access to Skype so families can be contacted privately.

Families felt that at the moment ATU’s should come with a health warning a bit like cigarettes. **They can seriously damage your health.**

What needs to be in place

There needs to be **local, small and specialist inpatient provision** for those people who might need it. Too many people are getting sent out of their local communities, away from family and neighbourhood and this causes great distress. This provision needs to be part of **an integrated pathway of support for people that links prevention, support and returning to the community.**

If people are admitted to inpatient provision the experience must be **therapeutic** and not detrimental to their long term health and wellbeing. Safe is not enough – it is about health and wellbeing - structured therapeutic support – delivered in a person centred way. Assessment time frames should be in place, and simple things are important – like people saying hello and goodbye on shifts. Staff need to be skilled in working with people who challenge and people with autism, and work in a person centred, family friendly way.

Services need to work collaboratively with families. There is a culture of seeing families in a negative light rather than recognising the important role they can play in promoting the wellbeing of their family member. Families should have more power and need to be involved on a day to day basis and at an operational and strategic level. There should be **written agreements with families** as to the length of time their relative will be admitted for. This should be reviewed jointly if things change.

There needs to be **better monitoring of services and accountability**. Those who monitor services are too ready to listen to clinicians at the moment. **Robust safeguarding** procedures need to be in place.

There should be **clear, well written leaflets for the person, their family and community support staff**. Leaflets should include:

- What to expect on admission. The role of each professional in assessment and treatment.
- How it is going to be implemented/ achieved.
- The approach to support / interaction eg – use of medication, functional analysis and PBS methods.
- The Outcomes / goals of Support
- The communication – approach but also who / when
- Information on listening to and involving families - history- how to communicate

&support

- Discharge planning from the beginning
- What and how things recorded
- What person centred activities are on offer

Coming home/back into the community

What worked well?

Having the right staff team with the right expertise and good hands on management is really important. A staff team that is prepared to ‘tough it out’. This happened when professionals were prepared to listen to families.

Good advocates and others who were prepared to advocate – such as the community care lawyer, a psychiatrist who agreed not to section a family member, supportive friends and the CBF.

Families learning about the Mental Capacity Act and the Human Rights Act – section 8.

Being an assertive parent.

What didn’t work well?

Families reported that services didn’t work well together, and did not engage when needed. For example in one area the learning disability team would not work with the individual until he moved in, as he wasn’t registered with the GP. Failure to share information meant that medication had to be prescribed by the psychiatrist without access to medical history. There were problems getting input from social services. There were arguments about between health and social services about placements and funding, and examples of the families being left to sort things out for themselves. One family reported that the psychiatrist's ‘service specifications’ for their relatives discharge was ignored by the social worker, who responded that there was nothing in the ‘service specifications’ that meant they had to be followed. *Not following the ‘service specifications’ for my son’s discharge lead to further and ongoing detrimental care after he was already traumatised from his hospital experience*

Families were not listened to leading to failed placements. . A diagnosis of severe auditory processing was also ignored by social workers for three years until a ‘best interests’ meeting with a lawyer was present as the families advocate meant they were listened to. There was no co-production. In one case it took a petition to change things. There was a power imbalance.

One family talked about how the new staff team needed to spend much more time with their son. Although they had visited the in-patient unit, with hindsight, much more needed to be done.

Overall there was a feeling that *our children are not valued and denied basic human rights, opportunities and skills.*

The bewilderment of being in such a poor human rights care system in a modern democratic EU country and not knowing where to turn to for help, feels like XXXX and I have been shipwrecked for years on our own land. Six years after his transition we are now getting nearer to him having a reasonable quality of life by asking for a 'home based programme' funded by the Direct Payment Scheme.

What needs to be in place?

There needs to be robust **planning for difficulties**. Good **outreach support staff** are critical to this.

Services need to be **jointly commissioned** and there needs to be joint ownership, including families. Health and social care services need to work together and disagreements about funding should not result in failure to provide timely and appropriate support. Currently there is a sense from children's services that they are only planning up until 18 years of age. There needs to be **planning for life and better transition**.

Social workers need to be trained to work with people with autism and people who challenge. The training should involve families – and listening to families, so that people get the right placements. *Put in the wrong environment, with the wrong care, challenging behaviour escalates, so social workers need to learn how to respond effectively to a known condition. (They would not be supported to put a diabetic on a cancer ward and expect good results, but when it comes to vulnerable people they can put them anywhere they like).*

Small, local, low stimulation accommodation for people with complex needs and challenging behaviour, where family and friends can continue to give support and maintain relationships, staffed by people trained to work with people with complex needs and challenging behaviour.

Staff who have **good communication skills**, and understand sensory overload, and who can use social interaction programmes such as intensive interaction, gentle teaching Son-Rise and Handle. *'Professionals working with autistic people and not knowing that autism is a 'triad of social impairments', is a bit like finding a builder who does not know how to mix cement.'*

When things go wrong there needs to be **legal aid** to challenge poor service decisions

Conclusions

People with learning disabilities and families raised many common issues that should be addressed by the new service model. Prior to people being admitted to assessment and treatment services, families found they were not listened to, their relatives were not adequately assessed or understood, there was a failure to plan ahead, and lack of appropriate services. Good person centred, preventive care and support services, including intensive response services, working across health, social care, child and adult services, and of course listening to families, could all have helped prevent admission.

With regard to in-patient services, people with learning disabilities said they worked well when people felt safe, were supported to get well, had things to do, were enabled to stay in touch with home, and there was good advocacy. Families also mentioned skilled staff teams who avoided using medication and restraint where possible, and who listened to families and others who knew the person well. Local services were important.

In-patient services didn't work when they provided nothing for people to do, effectively de-skilling people, where there was no therapeutic input, where they were restrictive and unsafe, where families struggled to stay in touch and were not listened to. The experience of in-patient services for families and for people with learning disabilities was often traumatic and damaging. People with learning disabilities said that communication in the units was often very poor. People were not valued and got stuck in the system. Although advocacy was helpful, some was more helpful than others.

Small, local in-patient units need to be in place, with appropriate person centred therapeutic input, and an integrated pathway of support back to the community. Services should work collaboratively with people with learning disabilities and families, and information should be available in appropriate formats – as well as support to understand the information. Services need to be well monitored, and accountability should be built into the system. Advocacy needs to be readily available and understood.

With regard to returning to the community, it worked well when there were good links between the hospital and the community, and good planning, but this was quite rare. There needs to be good forward planning, jointly commissioned services and joint ownership, appropriately skilled teams, and good listening to families and to people with learning disabilities, including self-advocacy.

It will be important to use the experiences of people with learning disabilities and families set out in this report to improve the quality of services, as well as investing in training from people with learning disabilities and families to staff at all levels of organisations from senior management to front line staff. It will also be important for work to happen at a local level so that people with learning disabilities and families can see positive change quickly.

The most important message from people with learning disabilities and families was – please listen, and work with us!

Appendix 1

Questions for families in relation to the development of a New Model Service – as part of the post Winterbourne – Transformation programme.

Open ended questions that can be mapped against the *Getting It Right / Mencap/ Oxfordshire* frameworks and Nice Guidelines

Family carer

Family member

Three dimensions:

1. Staying well, staying safe in the community

1a What worked well?

1b What didn't work well?

1c What needs to be in place?

2. ATU

2a What worked well?

2b What didn't work well?

2c What needs to be in place?

3. Coming home/ back into the community

3a What worked well?

3b What didn’t work well?

3c What needs to be in place?

Other questions:

Did you ever meet the commissioner?

Key decision maker/clinical lead?

Named person?

Quality of the information?

Where did you get your support?

Three keys messages you would like to feed back to the reference group?

1.

2.

3.