



Department
of Health

Learning Disabilities

Good Practice Project



national forum
of people with
learning disabilities



National
Valuing
Families
Forum

Learning Disabilities

Good Practice Project

This project was completed under an action from *Transforming Care: A national response to Winterbourne View Hospital*

Report written by Jo Hough (National Valuing Families Forum), who led the project with Kerry Martin (National Forum of People with Learning Disabilities)

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Everyone who submitted an example of Good Practice.

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Foreword by the Minister for Care and Support



I had the pleasure of hosting an event in April 2013 when people with learning disabilities, family carers and colleagues from the Local Government Association, the Association of Directors of Adult Social Services, Think Local Act Personal and the Joint Improvement Programme, set up under *Transforming Care*, came together to celebrate good practice from across the country.

My particular thanks go to the excellent team of ‘checkers’ – people with learning disabilities, family carers and key stakeholders – who visited six services selected by people with learning disabilities and family carers as being the best from over 80 examples of good practice covering health, social care and public health provided in response to my request in November 2012.

The whole project began over 12 months ago when the National Valuing Families Forum and the National Forum of People with Learning Disabilities, who attend the Learning Disability Programme Board, were challenged to find examples of services that improved the health and lives of people with learning disabilities. They looked for services that met key indicators of excellence including a move towards integrated services, a commitment to personalisation, community capacity building and a capabilities approach to disability focussing on people’s strengths. Above all, they looked for examples of co-production where people who use services are involved in planning and in some cases delivering them.

The project itself serves as a shining example of co-production. It shows what happens when a Government Department puts people with learning disabilities and family carers in the driving seat to identify what they think is good practice. The results were extraordinary. The six projects that were presented, following visits by pairs of ‘checkers’ were diverse, inspiring and demonstrate what is possible and what good looks like.

The working group overseeing the project and led by Jo Hough from the NVFF and Kerry Martin from the National Forum had the immense task of considering over 80 separate examples and deciding which best fit the key indicators. What was sobering and equally information was the number of services put forward that, from the paperwork provided, did little more than meet minimum standards and in some cases illustrated the less good in terms of lack of person centredness and adherence to out-of-date models of care.

But the good practice was very good indeed. In Gloucestershire we heard how people with learning disabilities, trained as quality checkers, visit care homes, including at night time, and point out simple practical things to improve people’s lives. They witness at first hand what life

is like for people living in the homes and, from their experience, what will make people's lives better.

From Norfolk, we heard about good work improving access to public health. We know that people with learning disabilities have worse health care and die earlier than others. This project helps in our understanding of bringing good health outcomes to everyone.

In Hackney, I was really interested to hear about a project that enables shared ownership and we have included here details about how it can work. It was inspiring to hear how someone's life was transformed as a result of having her own flat and choosing how she wants to live day to day. This does not have to be a one off example. We want to see it replicated across the country.

The checkers visited a project in Oxfordshire designed to provide supported living for young people who would otherwise be in secure services. It was very encouraging to see how this worked in practice. It is central to the work coming out of *Transforming Care* – demonstrating how people moving from institutional care can have quality of life with independent supported living. Both providers and commissioners play a crucial role in making this happen.

A project from the Open University showed how drawing up individual Life Maps gives a better understanding of how people with learning disabilities have lived their lives. It can result in improved support from families as people grow older. The project also reported on the life and work of Mabel Cooper, who sadly died before the checkers could meet her. Mabel visited primary schools to talk about her life, including her years spent in an old long stay institution. She was passionate about communicating her life story and breaking down barriers to understanding people with learning disabilities.

Finally, from Merseyside we learnt about innovative approaches to meeting the health needs of people with a learning disability who have dementia. It demonstrated great practice with much to learn from the relatively simple things that can make an immense difference to people's lives.

One of the aims of the whole project has been to spread good practice and we hope that this report will be widely read and that commissioners and providers as well as people who use services and their families and carers will want to find out more. We have included the 20 projects that reached our long list with brief descriptions and contact details.

The project has also shown us that there is much to do in bringing every area up to the standard of the very best. This is the challenge that we face working through the Joint Improvement Programme to improve people's lives locally.

Transforming Care: A national response to Winterbourne View Hospital – the Department of Health Review Final Report, says that by June 2013 everyone in NHS funded care will have care plans. Putting these plans into action, by June 2014, everyone inappropriately in NHS inpatient services will move to community based housing. I want to broadcast success stories but also let the public know when this isn't happening.

It is a national imperative to transform how people with learning disabilities receive care and support and to put them at the very centre of service design, development and delivery. We have seen how this can be done through the examples in the good practice project. This has all been about giving people good lives, not institutional care, built on strong local leadership and co-production. I am determined to bring change to every area across the country.

A handwritten signature in black ink, appearing to read 'Norman Lamb', with a horizontal line underneath the name.

Norman Lamb
Minister for Care and Support

Section 1 – Easy read summary

1. Background and things we found out

The Good Practice Project



The project is all about finding places where services for people with learning disabilities are very good.



It aims to get people talking to each other to make services better.



It was a response to the abuse at Winterbourne View. This was an “Assessment and Treatment” centre. People with learning disabilities lived there.



The TV programme “Panorama” found out that people were being badly hurt by staff. Managers and staff did not make sure that people were safe. This was wrong.



Lots of work is being done by the government, charities, the National Health Service (NHS) and local councils. They want to make sure this does not happen again anywhere else.

The Good Practice Project is part of that work.

What is good practice?

People who worked on the project agreed that good practice includes:



- **People working together**
People with learning disabilities should help plan their own services and in some cases, make them happen



- **Looking at people's strengths and skills**



- **Helping people to live in the community**



- **Services working together**
(social care, health, housing and leisure)



- **Planning services around people's skills and interests**

Good practice is about what people with a learning disability and their families think, not what the Department of Health (DH) or service providers say.



The Minister for Care and Support asked people to tell him about good services. He asked all the leaders of councils and the National Health Service (NHS).

About the examples



People sent us more than 80 examples of good practice from all over England. We chose six.

We liked examples that:

- Make people's lives better
- Find or do things in new ways
- Might work well in other parts of the country
- Support people of different ages or cultures
- Prevent people being moved away from their family and friends
- Support people with complex needs and challenging behaviour



What are “Complex needs”?

People with complex needs might:

- have more than one disability
- show challenging behaviour
- not use words to communicate

What we learned from the visits



We sent a team of people to look at the six examples of good practice we liked the best.



Each team included someone from either the Valuing Families Forum or the National Forum of People with Learning Disabilities.

We found that in the best services:



- Everyone works together right from the start
- People plan their services, with support from family and friends if they need it



- People are part of their community. This helps people to be happier, safer and valued.
- Support staff really care about how they look after people



Also, carers and support staff need help and support so they can carry on doing a good job and inspire others.

2: Examples of Good Practice

Example 1: Access to Public Health Services



The Health Improvement Partnership is about making sure people with learning disabilities in Norfolk get the same access to services as everyone else.

The project was started by Public Health Norfolk and Equal Lives.



To make sure everyone was working together a group of people looked after the project. They included people with learning disabilities and family carers.



They ran workshops. People in charge of services listened to people with learning disabilities about using the services.

This helped them understand the problems people with learning disabilities have getting the help they need.



Here are some ideas the Partnership had:

- Spend money in a better way
- Help people talk to each other about what they need
- Help people learn about healthy living and communication



- Keep people safe from abuse

It is also very important for people with learning disabilities to help plan the services they need.

Services work better when people with learning disabilities work closely with staff and service providers.



This example showed good practice because:

- 1) It looks at the need for people to get help with using local health services. This shows they are **planning services around people's skills and interests.**
- 2) It is about **people working together.**

Example 2: 360° Quality Checking

This Quality Checking project was run by the council and the NHS in Gloucestershire.



It was chosen because it uses lots of ways to check for quality, including visits by people with learning disabilities. When they do quality checks they:



- Ask people what they think of the services
- Visit services to see how well they are doing

People who run services said:



- The project is really good
- They now think more about people's lives
- They know more about how to make services better
- It gives good reasons why they need to keep paying for good quality services



This example showed good practice because:

- 1) **Services are working together** and include people who use services and their families.
- 2) The project showed that making friends is important. This shows **planning services around people's skills and interests.**



Example 3: Supported living for people with complex needs



This project was run by Hackney Borough Council and Advance Support.

It is about supporting a person with complex needs to have more say over how they are looked after.



What are “Complex needs”?

People with complex needs might:

- have more than one disability
- show challenging behaviour
- not use words to communicate



The person’s name is **Xenia**. She lived in several places but they didn’t work out.

Advance Support found a place for Xenia where she could live on her own. It took three years. They worked with lots of people, including Xenia’s family.



Now she chooses the staff herself and does activities she likes. The staff check how she feels every day. For example, they noticed she didn't like rushing home for a change of staff at 2 pm so they changed it to 6 pm. Xenia felt much better.



Xenia feels safe in her home. She sleeps better. She talks more. She goes to college.



It costs £30,000 less per year to look after Xenia because she does not need two people at a time to look after her now.

In the future, Hackney Council and Advance want to help more people with complex needs live in the community.



This example showed good practice because:

- 1) There are many **services working together**.
- 2) All Xenia's needs were cared for. This shows **planning services around people's skills and interests**.

Example 4: Transition Support for Young People with Complex Needs



This example is run by MacIntyre Care and Oxfordshire County Council.

The No Limits project gives education to young people with complex needs in the community.



It gives them somewhere to live and teaches them skills for daily living.

Staff know about health, care and education. They help each person to choose who supports them.



Involving families helps people with complex needs to get good housing and be happy where they live.

The project supports 200 people. 6 people used to live in secure units.



This saves money because it costs less than high security units. It is good value for money.



The project shows people who fund services that education works well in the community as well as in school.



The Checkers visited three young men at home. Their behaviour can be difficult for the people who know them.



The No Limits team worked with their families to get them places to live and help them learn too.



Managers want to help people to take some risks, if this helps them to be happy with their lives.



This example showed good practice because:

- 1) The No Limits project gives each person more choice. This shows **planning services around people's skills and interests.**
- 2) MacIntyre Care works with the council, services and people who teach skills for life. This shows **services working together and helping people to live in the community.**

Example 5: Sharing Life Stories



This work by the Open University (OU) was about putting together life stories of people with learning disabilities.



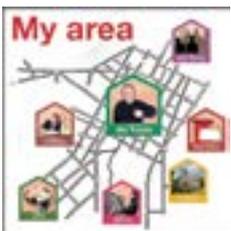
One part of the project was the work of **Mabel Cooper**. Mabel travelled around the world telling people about her life in a big hospital for people with learning disabilities. She also wrote a book.



She told her story in schools in London. This helped them talk about things like bullying and being treated differently.

Sadly Mabel died from cancer just before our team had a chance to meet her.

The project also had an OU student who worked with nine people to look at their life history.



They made a map of places they had lived, their family and people they met over their lifetime. This helped them to share their needs with staff and get better support.

This example showed good practice because:

- 1) It values the lives and talents of people with learning disabilities. This shows **looking at people's strengths and skills**.
- 2) It gets people to think about including people with a learning disability in everyday life. This shows it is **helping people to live in the community**.



Example 6: Support for People with Down's Syndrome and Dementia



This example was run by the National Health Service (NHS) in Merseyside.

It is for people with Down's syndrome who have memory problems that affect their daily life (dementia).

The project aims to:



- help people understand what dementia is by training families and support staff

- find out about health problems as early as possible



- help family members cope with the ways the person will change

- look out for early signs of dementia



They are sharing ideas with Liverpool University, Manchester University and other places.



This example showed good practice because:

- 1) It looks at every part of a person's life. This shows **planning services around people's skills and interests.**

- 2) It looks at how people can live with dementia. This shows **looking at people's strengths and skills.**

Section 2 – Background to the Project

The idea for the Good Practice Project was first proposed at a meeting of the Learning Disabilities Programme Board in December 2011, after a discussion between the co-chairs of the National Valuing Families Forum (NVFF), the co-chairs of the National Forum of People with Learning Disabilities and the former Minister for Care Services, Paul Burstow.

Designing and Planning the Project

The project required us to find examples of good practice in services for people with learning disabilities. At the initial planning meeting, NVFF representatives suggested that the whole project should itself be an example of good practice and co-production. This meant that all the people who have an interest in good practice should take part in the work. With this in mind, a steering group was set up, which included the following people:

- Geoff Baines, formerly Learning Disabilities lead for NHS South of England
- Tim Hind, Local Government Association (LGA)
- Rachel Holynska, Deputy Director People Communities and Local Government, Midlands and East (DH)
- Jo Hough, NVFF
- Kerry Martin, National Forum of People with Learning Disabilities
- Bill Mumford, Chair Think Local Act Personal (TLAP)
- Pam Nixon, Learning Disability Policy Team (DH)
- Andrea Pope-Smith, Association of Directors of Adult Social Services
- Vicki Raphael, NVFF
- Stephen Taylor, Hampshire County Council

In November 2012, the Good Practice Project was officially announced by the new Minister for Care and Support, Norman Lamb. A set of indicators of good practice was agreed, and a framework for submitting examples was published and sent out with a letter from the Minister to all Chief Executives of local authorities, and to the NHS.

The good practice indicators were:

- **Co-production** – involving service users in planning their services and in some cases delivering them.
- **A capabilities approach to disability** – looking at people's strengths and what they can do, rather than looking at what people cannot do for themselves.

- **Community capacity building** – where people can gradually rely more on community-based support.
- **A move towards more integrated services**, bringing in care, health and often housing and leisure.
- **A commitment to personalisation**, not as a cost-cutting measure.

Members of the steering group were pleased and surprised that more than 80 examples were received before the deadline on 13th December 2012.

A small working group was set up to make sure that the project would be completed with the full involvement from both Forums and the Department of Health. The members were Kerry Martin (National Forum), supported by Sally Scott and then by Helen Nicolson, Jo Hough (NVFF), Pam Nixon (DH), and Anita Wadhawan (DH).

Selecting Good Examples

On 18th December 2012 we held our first working group meeting. We looked at the first 20 examples that had been sent in, and we found some very good ones.

The group agreed that because of the high number of examples (over 80), each group member would look at the rest of the examples and each choose the 5 or 6 examples that we felt met the project's "indicators".

We decided that as well as using the indicators, we should be looking for examples that suggested new ways of doing things, and examples which might work in different areas of the country. We tried to include examples that could cover a very broad range of people who use learning disability services, across ethnicity, age, and geographic location. We decided not to focus only upon services that support people with complex needs and challenging behaviour, and to look at services which improve the lives of disabled people and prevent people from being placed out of their local area.

It was hard work reading through all the examples, but it was also very interesting. We noticed that some examples of good work that we each knew about had not been sent in, and we thought that perhaps some smaller projects and services were too stretched on resources, so might not be able to find the time they needed to write about their work within the three weeks we had given for replies. After the deadline we were told by some service workers that they had not heard about the Good Practice Project, which was surprising as the Minister had written out to all Local Authority and NHS Trust Chief Executives.

There were some examples that we felt were described in ways that sounded more service-centred than person-centred. We also found that lots of examples described similar ideas, such as quality checking, and we decided that we would have to choose between them so that we did not choose more than one example on each topic.

Some examples have been around for quite a long time, which we agreed was good for continuity, as long as they are keeping up with new ideas and changing the ways they work

to suit what people need. Some organisations sent in lots of examples about each aspect of their work, which we thought could have been combined to make a stronger case. We felt this might have given us a better overall view of how people experience the service.

When the working group met again on 14th January 2013 to make our “long-list” of examples that we would share in our final report, we were all quite disappointed. We had been encouraged by reading the first 20, but only a small number of the ones that came in later were particularly good, and some were quite worrying.

Some examples seemed to suggest that because their service met minimum standards, it counted as a Good Practice example. We didn’t agree with this, and we wondered how these examples could improve in future, if they think that minimum standards are “good practice”.

One example described a service which used “personalised place-mats” to give information about people’s food choices and the support they need when eating. It suggested that people could take these place-mats with them when they are out in the community. We felt this was not very good for people’s dignity, and could make them more vulnerable to abuse.

There were also a couple of examples which talked about improving things for staff, but without saying how this makes things better for the people they support.

Some examples seemed to say that involving people in designing or changing services was about people being asked what they thought after the big decisions had been made. We didn’t think these examples met the co-production indicator. In others, where a service was provided for people with learning disabilities or families this was used as an example of involving people with learning disabilities and family carers.

Other examples were written using lots of words that seem to fit with the indicators, but then referred to people as “service-users”, which, although often used by lots of organisations and groups, is a term that many people with learning disabilities and family carers do not like, because it implies that the service is more important than the person. We agreed that if a collective term is needed, we would prefer to see the term “people who use services” or even better “people”.

We were also disappointed about the number of examples that didn’t have an Easy Read summary, which the Minister had asked for in his letter. In some cases this was probably a genuine mistake, but one example said that they didn’t send an Easy Read because there was no standard format for Easy Read documents. We wondered about how they would communicate with people who have learning disabilities, if they don’t usually provide Easy Read documents.

For all of these reasons, it was quite easy for us to agree on the examples that looked really good, and we found that our choices had overlapped quite a lot. To help us make a shortlist, we asked the wider Good Practice Steering Group members to look at our long-list and choose the ones they thought were outstanding as well as the ones they would be interested in visiting as Checkers.

The steering group agreed upon 10 examples that looked very good. We then decided that we should take out of the short-list any examples that had already been written about recently as national examples of Good Practice (for example one which had been published in the Department of Health Review of Winterbourne View *Transforming Care*). It was then quite easy to choose the final 6 that would be visited by Checkers.

We also asked the steering group to volunteer as Checkers themselves, and we invited other people from the National Forum and National Valuing Families Forum to be Checkers. We wanted two checkers to visit each project; one checker from either the National Forum or the NVFF, and the other from the wider steering group.

Arranging and Completing Checkers Visits

During the process of arranging the visits, we spoke to the local people who work in the services and got an idea of what they could show our Checkers. We noted that they all seemed to be closely involved with the people they serve, and very understanding and respectful of their needs and wishes. They also had no hesitation at all in welcoming a visit and were confident about answering our questions and deciding how they could help our Checkers to gain an insight into their work.

We designed a Checkers sheet so that we could get a broadly similar range of information about each of the examples, such as what had been easy to achieve, and what was more difficult.

The Checkers carried out their visits and provided their feedback. This was then summarised for the descriptions of the examples given in the Section 3 of this report.

The local contacts for each of the examples were offered the opportunity to make corrections and suggest improvements to the descriptions before they are shared, and we were relieved that everyone responded very promptly, given extremely tight deadlines.

In Section 4 there are also brief descriptions of all the other examples that were selected for the “long-list” by the members of the working group.

Sharing the Good Practice Examples

Both the National Forum and the National Valuing Families Forum representatives are very hopeful that this report will encourage people who commission, design and deliver services to carefully consider whether the examples described here could be copied or adapted, to improve people’s lives in many more local areas.

Section 3 – The Six Selected Examples of Good Practice

Example 1: Access to Public Health Services

Submitted by: Public Health Norfolk & Equal Lives (formerly Norfolk Coalition of Disabled People)

Location: Norfolk

Checkers: Dawn Johnson (National Forum) and Tim Hind (Local Government Association)

Email: info@equallives.org.uk

Phone: 01508 491210

Website: www.equallives.org.uk

Address: Equal Lives, 15 Manor Farm Barns, Fox Road, Framingham Pigot, Norwich, Norfolk, NR14 7PZ

The Health Improvement Partnership project came out of conversations between people working in Public Health Norfolk and Equal Lives (formerly Norfolk Coalition of Disabled People).

This example was selected for our report because it addresses a very common issue about people needing easy-to-access information on local health services. With responsibility for public health services passing to local authorities, it is an issue that will benefit from being addressed in all local authorities sooner rather than later.

This example was also chosen because the project has been carried out in full co-production, by talking to people with learning disabilities about their stories and ideas and using these to advise professionals about the barriers that people with learning disabilities have in accessing public health services.

It is a time-limited project that intends to make a difference for the long term by changing the way that information about health services is designed, and improving the ways that information is delivered to people with learning disabilities. The aim of the project is to provide action-based recommendations, information and advice leaflets, good practice guides on accessibility, and recommendations for training/development

The project is about people with learning disabilities working with professionals and others to make sure that disabled people get equal access to services. It was agreed that collecting

the experiences and advice of people with learning disabilities was the best way to understand the difficulties people face. The project has been designed to use these experiences to make recommendations about how to improve access – and so improve health outcomes.

To make sure that there was full co-production, a steering group of people with learning disabilities and family carers was put in place to oversee the project. A series of workshops were planned with a range of commissioners, providers and disabled people to identify the problems and recommend changes. It was agreed that doing this would take a year.

Building networks has been central to the way the project operates. The workshop approach also ensures that networks of people with learning disability, family carers, commissioners and providers can hear direct from each other about problems and challenges, and about solutions

The steering group and project officer have worked out:-

- Who they need to talk to. This includes people with learning disabilities from all areas of Norfolk, people living in a range of different settings; people working and training in different places; people of different ages and with different levels of need and disability; family carers, and also the people providing services.
- Key priorities. These were identified as healthy eating, keeping active, health checks and screening, communication and stopping smoking.
- The steering group also identified two big issues that need to be addressed but that will need separate projects over a longer time period. These are sexual health and mental health. The things that need doing on these are:
 - Sexual health – changing attitudes, sexual health advocates and improved access to information and advice.
 - Mental health – changing attitudes, better (and clearer) service pathways, and improved communication and information.

It was quite hard for the steering group to cover the whole county, as Norfolk is big and mainly rural, and some areas have no advocacy networks or organisations for the project to tap into. There have also been issues with getting views across to some professional groups who “see the wheelchair, not the person” or who “don’t want to listen”. There are also concerns that some existing problems with accessing health services could be made worse by focussing on solutions that are “cost-driven” rather than “health-driven”.

When our Checkers asked about the value for money of this project, the steering group said that they could point to a number of things that are currently poor value for money (for example, resources that are under-used), and they have a clear view about how things can be improved. They also said that they have worked out lots of useful tips to pass on, for example taking time with communication, and enabling people to learn to cook, to support their healthy eating.

The project has tested co-production between people with learning disabilities, family carers and professionals. This has emphasised people’s capabilities and highlighted the importance of disabled people being involved in service design and delivery to “make things work”. It has also shown the value of building and supporting networks of disabled people/professionals across the county.

Our Checkers felt that it was clear that members of the steering group are thoughtful about the impact of austerity/welfare reform, the importance of issues about confidentiality, but also ensuring that people are safe, the importance of “cross cutting” themes like communication, and also of dignity and respect for people with learning disabilities.

Example 2: 360° Quality Checking

Submitted by: Gloucestershire County Council, NHS Gloucestershire and Gloucestershire Voices (a self-advocacy organisation)

Location: Gloucestershire

Checkers: Jo Hough (National Valuing Families Forum) and Vicki Raphael (Steering Group and NVFF)

Contact: Agy Pasek

Email: agy.pasek@gloucestershire.gov.uk

Phone: 01452 328647

Address: Learning Disability Commissioning Team, Gloucestershire County Council, Shire Hall, Westgate Street, Gloucester, GL1 2TG



This example was chosen to be visited by our Checkers because it uses a number of different ways to check for quality, including visits by people with learning disabilities. It also gives evidence of positive impacts for all the people involved, from providers to people who use services.

The Quality Checking project in Gloucestershire is co-produced by Gloucestershire Joint Commissioning Team and Gloucestershire Voices user-led organisation.

The project has the support of people and organisations who provide services, as well as people who commission services and people who use services.

The quality checking process has 3 parts to it:

- A “Q360” survey, which is a voluntary questionnaire offered to people who use care and support services, asking what they think about the support they get. Questionnaires can also be completed by other people who know the person well, such as family members and friends, staff working in the services they use, people they meet with regularly in the community, and so on. By doing this, the council collects lots of feedback from different points of view about the quality of the person’s life, and gets an insight into how well service providers are fulfilling their contracted responsibilities.
- A programme of quality checking visits by Gloucestershire Voices, who have trained people with learning disabilities who use support themselves to be experts by experience, to ask people in residential services what they think is good about where they live, and what might be better.
- Unannounced visits by Gloucestershire Joint Commissioning Team, to find out if people are being supported and cared for properly at all times, including at night.

The people who are Quality Checkers for Gloucestershire Voices talked about having increased their confidence, and being proud of the work they do because it can change people’s lives. They “always look for the good in the services” they check. They said it was quite easy to recruit new quality checkers, as they were often asked by people living in the settings they were checking about how they could get more involved.

The providers who presented their views at the visit said that they were impressed by many aspects of the process. For example, they said it was “the first time there has been a chance to empathise” with people and they felt they were learning together. They said that the quality checking framework addresses lots of angles and that it helps them to think about “quality of life, not just quality of service”. They said that at first, the staff perceptions of the checking process were very diverse, but that they get a useful report “way beyond CQC compliance”. They also commented that “without someone checking, we wouldn’t ever know how to get better”.

The commissioners are very positive about the effectiveness of the quality checking and they believe that over time, the accepted standard will become higher. They see the quality checking process as an investment which gives them the evidence they need to carry on commissioning good services that people want, and helps providers to keep on improving

their services. Other initiatives are developing from the learning about what people said needed improvement, such as inviting people's circles to get involved in the quality survey. Knowing more about people's social networks means that people who may have limited community connections can be identified, and referred to an organisation that has been commissioned to address social isolation. The Joint Commissioning Team strongly believes that being socially isolated is 'high risk', so this is a key part of the quality programme

Our Checkers were impressed by the successful co-production shown in this example, from user-led organisations, to politicians at the local council, to people working in the care settings. The Checkers noted that there were a lot of "softer" outcomes from the project. For example, because the Gloucestershire Voices Quality Checkers meet people in different settings all around the local area, there were more opportunities for people with learning disabilities to make friends with, and feel connected to, people in similar circumstances.

The project has recently received further funding and along with continuing its existing work, the plan is to expand the involvement of family carers in the process, and to increase people's connections and involvement with community activities. They will also try to engage with a number of services within the county that are not currently commissioned by the County Council.

Example 3: Supported Living for People with Complex Needs

Submitted by: London Borough of Hackney and Advance Support

Location: Hackney, London

Checkers: Marcella Cooper (National Valuing Families Forum) & Bill Mumford (Think Local Act Personal)

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This example was chosen because it shows how an extremely personalised support package can be a good alternative to a more restrictive placement for people with complex needs. The person highlighted in this example, Xenia, had been living in different residential settings, none of which worked well for her, and which had always broken down after a period of time. Xenia now lives in a property that she partly owns under shared ownership with a local Housing Association.

The Advance Support team had begun working some years ago with the Tizard Centre at the University of Kent to try to create better support provision for people in Hackney who have complex needs and behaviour described as challenging. They also worked with local housing providers to help them understand the particular needs of the people they support, and managed to find a suitable property for Xenia that she would not have to share with anyone else.

Our Good Practice Checkers were pleased about the degree of co-production that has taken place to ensure that decisions are made in Xenia's best interests. Xenia's sister was very much involved as she has guardianship of Xenia. The mortgage is in Xenia's name but her sister signs on Xenia's behalf. Should anything happen to Xenia's sister, then Advance will become the deputy and will support Xenia with her financial affairs.

The scheme took three years to set up, and it was hard to find a suitable property. Deputyship took a very long time to set up. It also took a long time explaining the shared ownership concept to Xenia's family, and the work involved with the housing association.

The longer term intention of Advance Support and Hackney Council is that more people in Hackney who have complex needs will have shared ownership, which will empower them to lead an independent life, but with support. Xenia feels safe and secure in her home, and it was clear that Xenia was leading an interesting life. Advance is also promoting shared ownership. They told our Good Practice Checkers that they have a very good relationship with the health team and other professionals in Hackney.

Advance is always learning, does not take anything for granted, and will keep on refining their service as necessary. Xenia's support needs will change, and her support will be adapted to suit her. The methods used to record Xenia's mood and response to activities enables staff to understand what she likes and dislikes. When there is a change in her behaviour, the incidents are referred by staff for discussion with the behaviour specialist at Advance who has had training in positive behaviour support techniques from the Tizard Centre. They then observe and carefully analyse the possible causes of the change. For example, Xenia began to show distressed behaviours about a year ago, and staff found that there was often a rush to get home by 2pm when the staff handover between shifts happened. They tried changing the shift handover time to 6pm and this worked much better for Xenia, as it meant that there was less interruption to her activities or outings during the daytime.

Xenia's sister has been very pleased with Xenia's progress. And Xenia's positive behaviour has been commented on by members of the public who knew Xenia before she moved into her own home, as they can now approach Xenia in public places.

The cost of supporting Xenia so far has fallen by £30,000 a year, mainly because Xenia no longer requires two people to support her in the community. She sleeps through the night, and her behaviour has become less challenging. Xenia is happy and has a good social life. Xenia attends college and her daily activities have enriched her life.

Xenia knows who is supporting her – she chooses the staff herself. The staff ensure that Xenia is engaged in activities she likes. Xenia is told the night before and she is reminded again in the morning. The staff check her behaviour as they are reminding her again, and they know if Xenia really wants to do an activity. This approach has reduced behaviour that can at times be described as challenging.

Our good Practice Checkers were very impressed at how well Xenia was supported during their visit. They said that it was quite busy and noisy with all the questions they had to ask, but the staff supported Xenia so well that it was easy to see how proud and happy she is.

Example 4: Transition Support for Young People with Complex Needs

Submitted by: MacIntyre Care

Location: Oxfordshire

Checkers: Shirley Corbett and Rachel Mason (National Valuing Families Forum) and Steve Taylor (Hampshire Local Authority)

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This example was selected as it offers a less restrictive and more personalised approach to young people with complex needs who might usually be referred to adult assessment and treatment units upon reaching adulthood. The project combines a full time education and care and support package. The service draws various funding streams together with the intention of providing a community-based supported living option for small groups of young people, blended with community based education. MacIntyre staff are skilled in education, as well as care and support, which makes the No Limits college and 24/7 support package work so well.

The project started when MacIntyre Care was approached by Oxfordshire County Council to look at developing services for young people with complex needs and challenging behaviour, currently in or at risk of moving to secure settings.

Oxfordshire County Council in partnership with MacIntyre was able to create a bespoke service around each young person involved, made easier by the tradition of pooled health and social care budgets in Oxfordshire. A team of staff is recruited by MacIntyre Care to meet the needs of each particular young person. All of the young people are able to purchase their care through an individual budget with an addition of education funding to ensure the young people are able to live and learn relevant skills in transition to adulthood in their local community, the place where they will be in the long term.

MacIntyre Care works hard to recruit staff appropriate to the service and to the young people within the service. They carry out a process of matching staff and use personality profiling. The young people and their families are very much involved in the interview/matching process. They also create a 'wish-list' with the young person, which assists the matching process.

MacIntyre has developed very trusted relationship with the Local Authority, and with a particular children's commissioner. They have used their 'My Way' transition service that looks at creative ways to use individual budgets, using a brokerage plus service. Not only does the service look at options; it is also fundamental in setting up provision, working with all stakeholders; the young people, families, housing providers, support providers, the local authority and other professionals.

The No Limits project supports people with both education and social care needs to meet their chosen outcomes, and often works with people who would traditionally fall between services. MacIntyre Care employs Community Learning Facilitators who work with the young people to facilitate learning and provide support. They encourage teaching of basic living skills and 'being a part of the real world'.

The move from a secure setting into more independent living with community based support can be difficult to achieve. Finding appropriate accommodation for several people with complex needs can be difficult. It is a challenge to help people to maintain tenancies, especially in residential areas. It has also proved difficult to work with several sets of parents for each residence, and to reach agreement on certain issues, especially the property and the location. This requires a very person and family centred approach to reach resolutions to ensure everyone involved is satisfied with the property and it meets the needs of each resident.

The broader No Limits project now supports around 200 people, with six people who were living in secure accommodation now being supported in the project.

The support the project has received from statutory agencies and professionals is enabling it to grow quite quickly and MacIntyre Care is confident of its long term sustainability. The No Limits scheme appears to be very good value for money. The alternatives to the supported community living would be high cost secure placements. The No Limits programme offers people an effective, value for money alternative to traditional institutional education. MacIntyre Care feels that their commissioners are very happy with the value for money their services offer.

MacIntyre Care could share a range of case studies with other commissioners or providers. They have expertise in both education and social care and are firmly of the belief that education can be anywhere, not just in a school setting.

Our Good Practice Checkers were impressed with what they were told about both the No Limits and My Way projects. Checkers made a second visit to see the No Limits project in June 2013 as the first visit in April was hampered by bad weather. On the second visit, the checkers visited a house designed for three young men with behaviour that challenges. The families of the three young men, who were from the same residential college, worked closely with the My Way team. Although not local, they had established a community in Oxford. Using good person centred planning to identify short term and long term outcomes and designing a 24/7 education and support plan was key.

The managers were very open about 'taking balanced risk and looking at the benefits of learning from the consequences of a choice'. MacIntyre want to encourage this approach in their staff and provide clinical supervision to talk through what is acceptable and positive risk management. Supporting staff and family carers to acknowledge the transition from child to adult is reflected in the style of support and resources provided (for example, there was no unnecessary labelling of cupboards as happened at school).

For the future, this example of good practice could lead to fewer placements in secure units and residential settings, security in your local community, and your own tenancy and building relationships with family and within the community. Unless local authorities invite MacIntyre to set up something similar at their local college, this scheme means that some people will be sent out of county in order to get access to it. Alternatively, this model could be adapted and duplicated by other local providers who are willing to commit to the educational and training of support staff to get the same results.

The learning from this project could be shared through life stories, sharing the educational approach with local colleges, sharing the excellent outcomes achieved with other local authorities and health commissioners and promoted as an alternative to out of county placements.

As a testimony to getting it right, a member of staff said, 'A young person who had challenging behaviour and a high negative profile in his community, once we went in and supported him in a person centred way the community wondered where he had been sent – he was still there'.

Example 5: Sharing Life Stories

Submitted by: Open University – Social History of Learning Disability Group

Location: London boroughs

Checkers: Kerry Martin (National Forum) and Rachel Holynska (Department of Health)

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This example of good practice was selected because it values the lives and talents of people with learning disabilities. It promotes the recording of people's histories as valued members of our society. It also helps us to think about how to change attitudes in society and get better at including people with learning disabilities in their local communities.

Part 1 – Telling Life Stories in Schools

This part of the Open University (OU) team's work focuses on the life and work of Mabel Cooper, who was diagnosed with a learning disability at the age of 13, and placed in St Lawrence's hospital. This was a large, long-stay institution for 2,000 people with learning disabilities. As attitudes changed and care in the community was introduced, Mabel asked to leave the hospital after 20 years there, and was placed in a smaller group home. She joined a local People First Self Advocacy Group in Croydon, and later became its Chair, and began to find out more about her own life history.

Mabel travelled to Canada, Australia and Ireland to share her experiences of her life in an institution, and to help other people to speak up about what life is like for people with learning disabilities. She also shared her story with children in primary schools, with the aim of improving their understanding of learning disabilities, and raising their awareness of how it feels to be treated in a negative way.

The school sessions with Mabel opened up valuable discussions about issues like bullying and people being treated badly if they are different. Our checkers thought this was a good way of helping children to think about acceptance and tolerance. The teachers were helpful in setting up the sessions with Mabel and found that they were useful and engaging for the children.

To continue this work, it will be necessary to identify other speakers, and to support them to take it on, which would need modest funding. The life stories could be recorded and embedded in lesson plans held on a website for downloading by teachers enabling the stories to reach a wider audience of children.

In January 2013, Mabel Cooper worked with Ellen Goodey (herself a young director who has learning disabilities) on a play which incorporated words from Mabel's life history into a play. This work could also be developed to take Mabel's life story into schools.

Sadly Mabel died in the same week that our Checkers' visit took place, having lost her battle with cancer. The OU team was pleased that Mabel's work had been recognised by the Good Practice Project. Our Checkers were sorry that they did not get the chance to meet Mabel in person.

Part 2 – The Staying Local social history project: life stories

This part of the OU work focused on collecting the histories of people who have learning disabilities. Some of the people telling their stories had complex needs, including limited communication skills. The life history research showed that keeping people in their local communities successfully was often due to good care being provided by families, and the support networks they built up informally in the local area. Short break services that helped families quickly in a crisis were also important. All of the people who participated in the research had "lost" parts of their life stories, and when these missing pieces were found, and shared with staff, it helped to increase understanding of people's needs and how they could be better supported.

Nine people were supported by an OU PhD student to find out about their history. Each person made a map of places where they had lived, with help from family carers. They found out about their family members, their old friends and local communities. Sometimes it put them back in touch with people they had not seen for a long time. The OU team suggested that making maps and recording peoples' life stories could help them get better personal plans to support them to stay in the local area, with links into their communities, instead of having to go into places like Winterbourne View.

One difficulty has been evaluating the work. The OU team aren't sure whether there are other similar projects that could be compared with this one. The life story maps were evaluated with people with learning disabilities and staff and the feedback was very positive. However using mobile interviews and maps to help people with limited communication share their past is a new area and so it is difficult to compare this work with findings from other projects.

The Staying Local Project was completed in 2012 and work has not yet started on finding funding to take it forward. Yarrow Housing is making a joint bid with the OU team to develop a Knowledge Transfer Partnership, which attracts national funding through partnerships with universities. If successful, Yarrow Housing will jointly fund a post for the people who they provide care for and who have complex needs, with the aim of skilling Yarrow Housing's staff to continue the life story work. A carers group in Oxfordshire is actively seeking funding to undertake this work with their sons and daughters.

There has also been a bigger idea about bringing together a group of the main universities that support research for people with learning disabilities with a group of providers to think about how they might share the learning and options for future funding. There may be other funding bodies to tap into, such as the new Academic Health Sciences Networks.

Our Good Practice Checkers asked about the cost of doing the life histories project to improve knowledge about people’s experiences and the support they may need. It seemed that the resource needed is a member of staff to work with the provider and a group of up to perhaps 10 people with complex needs, or with carers, to develop their story maps.

Our Checkers liked the mobile interviews and the idea of taking people back to places they know, to encourage them to talk about their early lives. They also thought that developing a partnership with a university to do this work was a good model that could be copied in other places.

When our Checkers asked how the work could be sustained, the OU team said that they are very willing to share their learning with other people who would find it useful.

Example 6: Support for People with Down’s Syndrome and Early Onset Dementia

Submitted by: Merseycare NHS Rebuild Service

Location: Merseyside

Checkers: Alison Owen (National Forum) and Andrea Pope-Smith (Association of Directors of Adult Social Services)

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This example was chosen because it offers an holistic approach to supporting people with Down’s syndrome who have received a diagnosis of dementia. It helps people to understand what the diagnosis means, and also offers their family members information and support about adapting to the changing needs of the relative they care for.

The aim of this approach is to ensure that people who have complex health needs are supported to have the best possible diagnosis and treatment, specifically in relation to early onset of dementia.

It is very important that everyone around a person understands how dementia impacts on their life. People can become labelled as being difficult to support and this can negatively affect their relationships and day to day activities.

Having an understanding of dementia enables families and workers to empower the individual. Training is an important part of this together with environmental adaptations and

ongoing support to families and staff teams to enable the individual to remain in their own home for as long as possible. This service provides bespoke awareness training packages for housemates who have learning disabilities, to explain about living with someone who has dementia, and the training is delivered in ways that work for the housemates as individuals.

Early diagnosis means that people who have Down's syndrome can access services as early as possible and be supported by people who have the training and support themselves to understand the person's dementia journey. Early diagnosis ensures that important changes to care packages can be addressed promptly when the need arises. Support is given to preparing family, friends and paid staff to manage the inevitable changes and challenges that dementia can bring. Appropriate treatment or interventions can be discussed or/and started, such as medication, or person centred holistic therapies.

Annual baseline screening helps with detection of early signs of dementia. This also allows the team to deal urgently with treatable illnesses that may not be related to dementia.

The team has had a lot of impact locally. For example, people with dementia and their carers have put together training packages that they can deliver to other health professionals such as dentists, staff in acute hospitals, and medical students, to raise awareness and improve understanding of the needs of people who have Down's syndrome and dementia.

This means that other people are recognising the signs of dementia and learning how to treat people equally. The training has been well received and has made a big difference to people's experience of using other services. Learning disability nurses regularly train medical students at Liverpool University. It has now been made mandatory that all third year medical students complete a module on learning disability.

They have also have shared links with Manchester University on the training they have delivered. They are looking at how they can share their good practice and ideas with other areas.

Irene Byrne-Watts who is the director of the service meets frequently with Learning Disability Commissioners to discuss service developments, funding and value for money. They do this by using real life experiences of people who use the service, looking at their past history and comparing that to the lives they live today. The service has also appointed Gill Goodwin (person centred planning co-ordinator) who works with staff across the service to ensure that the services provided are truly person centred. Having one-page profiles and person centred reviews has helped to identify health issues early on. Targets are monitored on a regular basis. Staff within the service who work with people who have Down's syndrome and dementia work closely with the Primary Healthcare Facilitators who are also based within the Learning Disability Service.

Our Good Practice Checkers felt that families thought the service was good value for money. For example, a family carer said, "Serena (who is a learning disability nurse) was my angel; she was there for me when I needed her, there was times when she would come to A&E with me and make sure the doctors were listening to me. Sometimes I would ring her at 3 am and she would come out to help me. A lot of time was invested in creating the care

package for my sister; the service looks at the whole package and how dementia affects the whole family.”

Our Checkers reported that the service was very interesting and said “It was good listening to their good practices, they include people with learning disabilities and their carers very well and are very personalised to each individual”.

Section 4 – More Examples of Good Practice

Short Listed Projects – Summaries and Contact Details

Organisation: Coventry and Warwickshire Partnership NHS Trust

Contact: Susan Fox

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Phone: 02476 315867

Website: www.covwarkpt.nhs.uk

Address: The Loft, Community LD Team, Coventry and Warwickshire Partnership NHS Trust, 60 George Street, Bedworth, CV12 8EA

Summary: The Top to Toe women's group was set up by community learning disability nurses 4 years ago to support women with a mild to moderate learning disability, with an emphasis on accessing health screening and enabling them to meet their own health needs using personalised health diaries. The group is outcome focused and encourages women to set their own achievable health goals. This is facilitated using accessible information and resources working in partnership with other professionals and agencies. Some participants have also been supported to co-present on subsequent Top to Toe groups. Top to Toe is now run county wide and has been shortlisted for a Health Service Journal award. The Buddy Group was set up as a response to the women's request for on-going support. The group meets on a weekly basis at a community café and is led by the women themselves with some support from a health support worker.

Organisation: University Hospital North Staffordshire

Contact: Professor Sue Read

Email: s.c.read@keele.ac.uk

Phone: 01782 679653

Website: www.uhns.nhs.uk

Summary: This example is about accessible information for people with learning disabilities who are going into hospital for treatment. A film was co-produced with and for people with learning disabilities about going into hospital and having an anaesthetic. It was also translated into Polish, which is the second most common language used by people in the local area.

Organisation: Plymouth City Council

Contact: People First Quality Checkers

Email: info@p1qc.com

Phone: 07866 467567

Website: <http://www.p1qc.com/>

Address: Devonport Guildhall, Ker Street, Devonport, Plymouth, PL1 4EL

Summary: This example describes Cornwall People First's quality checking service for adults with learning disabilities. The team includes people with learning disabilities, and as well as checking local services, they are developing tools to check how well personal budgets are working for people. People First Quality Checkers are a social firm who offer independent evaluation of any service that provides for people with learning disabilities within Plymouth, but also in Devon and Cornwall by arrangement. People First Quality Checkers are in their third successful year. The Quality Checkers are a team of people with learning disabilities who use services, making them 'experts by experience' and who are also paid members of the team. People First Quality Checkers give a real voice and power to people who use services and are committed to positive change for people with learning disabilities. Working with providers to deliver real service improvement, the Quality Checkers highlight and celebrate good practice wherever they find it. The Quality checkers have been reviewing social care services in Plymouth and Cornwall and were commissioned to do a series of checks within Devon for acute mental health services for people with learning disabilities.

Organisation: Hertfordshire Partnership University NHS Foundation Trust

Contact: Alison Muir

Email: Alison.muir@hpft.nhs.uk

Phone: 07825 948 727

Website: www.hertspartsft.nhs.uk

Address: Community Support Unit, 14 Stratford Road, Watford, WD17 4DG

Summary: Obtaining Feedback through Talking Mats. For people with learning disabilities, the ability to share views about what is important can be far removed from their day-to-day communication. In Hertfordshire Partnership University NHS Foundation Trust we designed a project to evaluate how inpatients with autism, severe learning disabilities and limited communication could give feedback on activities available to them, using a communication framework called Talking Mats. The mats opened a real opportunity for engagement and for people to express themselves. In some cases, the views expressed were completely opposite to what had previously been assumed. Feedback from the project was used to broaden the choice of activities offered. Training has been given to staff in the Trust and advocates nationally. There is a proposal to teach it to peer-listeners who work alongside service users. Mats are not for everyone, but they offer a powerful visual alternative to verbal feedback.

Organisation: Dimensions

Contact: Sanchi Murison

Email: enquiries@dimensions-uk.org

Phone: 0300 303 9001

Website: www.dimensions-uk.org

Address: 9-10 Commerce Park, Theale, Reading, RG7 4AB

Summary: A national not-for-profit support provider working throughout England and Wales, committed to delivering personalised support that improves the quality of life and enables people to make their own choices and decisions. Dimensions is using the Individual Service Fund model to personalise residential care in its services. People with complex needs and challenging behaviours are supported by a specialist high quality Behaviour Support Team to deliver outcomes that change people's lives in supported living and residential care.

Organisation: Surrey and Borders NHS Partnership Foundation Trust and Surrey County Council

Contact: Andy Erskine

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Phone: 0300 55 55 222

Website: www.sabp.nhs.uk

Address: 18 Mole Business Park, Leatherhead, Surrey, KT22 7AD

Summary: This example is about building local support services for young people aged 19 to 25 with autism and behaviours that challenge. This work is about building good local services in partnership with young people and their families, to prevent out of area placements.

Organisation: Cambridgeshire & Peterborough NHS Foundation Trust and Peterborough City Council

Contact: Mark Hall

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Phone: 01223 885714

Website: www.cpft.nhs.uk

Address: Block 7, Ida Darwin, Fulbourn, Cambridgeshire, CB21 5EE

Summary: The local mental health trust has set up a specialist team (Intensive Support Team) which has reviewed all out of area placements and developed a sound plan to return 20 people with very complex and long-term health and support needs who have been living out of area for some time. The team work very closely with the returnees and their families to secure appropriate housing and good support. This initiative is building a local infrastructure which should prevent future young people with complex needs leaving Peterborough and further is making considerable savings for commissioners which then can be re-invested into local services. Keeping people close to their families and communities is not just the right thing to do but makes good use of finite resources and moreover people can be checked upon more readily to ensure that they are safe and well supported to lead more fulfilling lives.

Organisation: Black Country Partnership Foundation Trust

Contact: Cliff Hawkins

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Phone: 01902 444326

Website: www.bcpft.nhs.uk

Address: 44 Pond Lane, Wolverhampton, WV2 1HG

Summary: This example describes a community-based treatment programme for men with learning disabilities who have a history of sexual offending. The programme builds self-esteem and coping skills, and reduces the use of secure residential services.

Organisation: Respond

Contact: Dr Noelle Blackman

Email: admin@respond.org.uk

Phone: 020 7383 0700

Website: www.respond.org.uk

Address: 3rd Floor, 24-32 Stephenson Way, London, NW1 2HD

Summary: Respond is running a pilot training scheme with a group of learning disability nurses and social workers. The training will enable the delegates to understand how early experiences of neglect and abuse in the lives of some people with learning disabilities can lead to challenging behaviour. The 'Respond Nurses and Social Workers' once trained would be based within learning disability teams nationally in order to identify and support the people with learning disabilities in their area with the sort of traumatic history that is likely to lead to challenging behaviour. The main aim of these newly trained professionals is to enable these identified people to remain in their own community. An important part of the role would be to identify those at risk of placement breakdown and then work closely with their staff teams. Initially we provide introductory training with the direct care staff giving them a psychological framework with which to understand the behaviour and its roots in trauma and to respond in a sensitive, consistent and informed manner. The Respond professional would then provide monthly clinical supervision to the team in order to keep the situation stable and robust. From time to time if there is a situation which threatens the status quo they will be poised to move in and work more closely with the team in order to quickly stabilise the situation.

Organisation: South West Yorkshire Partnership NHS Foundation Trust

Contact: Karina Hepworth

Email: info@kirklees-yot.org.uk

Phone: 01484 226263/01924 482118

Website: www.kirklees-yot.org.uk

Address: Somerset Buildings, Church Street, Huddersfield, HD1 1DD

Summary: The learning disabilities nurse in the youth offending team supports young people between the ages of 10 and 18 in identifying their abilities and needs, accessing services, ensuring that the delivery of the Court Order takes account of those abilities and that they are reflected in the delivery of the intervention used to ensure completion of their Order. The nurse provides training to staff across the service which includes the Youth Offending Team, magistrates, volunteers and victim liaison and restorative justice staff and is central to ensuring that all Orders are delivered to young people in a way that ensures that they can comply and complete their time in the service as easily as possible.

Organisation: Beyond Limits

Contact: Sam Sly & Doreen Kelly

Email: sam@beyondlimits-uk.org

Phone: 01752 546449

Website: www.beyondlimits-uk.org

Address: Office 2, The Business Centre, 2 Cattedown Road, Plymouth, PL4 0EG

Summary: Beyond Limits have been commissioned by NEW Devon CCG to develop local personalised commissioning/provider processes and tailor-made services for people who have experienced long term, multiple placements and institutionalised living because their behaviours have challenged existing services. We are piloting this through facilitating planning for 20 people currently in out of area Specialist Assessment & Treatment Units and then providing support using Individual Health Budgets. Outcomes so far are positive with people and families feeling listened to and involved, professionals engaging with the process, other providers starting to make changes to work in more person-centred and people's lives being enhanced by re-engagement with their families and communities when they return back to Plymouth. Beyond Limits carry out in-depth planning with people, match a team to the person and spend time building good relationships before the person comes back to a home of their own. As a provider we will remain small so that we can concentrate on making people's lives big!

Organisation: Cornwall Partnership Foundation Trust/Cornwall Adult Care and Support

Contact: Dr Celia Todd

Email: celia.todd@cpt.cornwall.nhs.uk

Phone: 01209 219251

Website: www.cornwallfoundationtrust.nhs.uk/

Address: Learning Disability Service, Trengweath, Penryn Street, Redruth, TR15 2SP

Summary: This is a loan service which provides tablets and small MP3 players with touch screen, so that people with learning disabilities and families can try them out as communication aids. It lets people find out for themselves whether there are other “apps” that may suit their particular needs. This example helps promote community inclusion because these gadgets are viewed as mainstream items and used by lots of people, rather than “disability aids”. The learning disabilities speech and language therapy team recognised the value of using tablet PCs and small handheld MP3 players with touch screens to support communication. There are a growing number of communication Apps that can help people with learning disabilities to communicate more effectively. Also these devices can run an electronic communication passport or just allow the user to take photo of activities as a stimulus for sharing a conversation. We were able to purchase a small bank of loan items so that people can try these out in a range of settings and demonstrate how this relatively inexpensive technology can enhance communication and inclusion. We are also developing drop-in sessions where people can come and explore this technology and share their experiences.

Organisation: NHS England

Contact: Martin Cattermole

Email: martin.cattermole@nhs.net

Phone: 020 7972 5760

Website: www.personalhealthbudgets.england.nhs.uk/www.nhs.uk/personalhealthbudgets

Address: Skipton House, 6th Floor 202, 80 London Road, London, SE1 6LH

Summary: This example describes how personal health budgets can be used as a direct payment to buy care and support for people with complex health needs. This is a Pilot programme to offer personal budgets to people who have Continuing Health Care funding, with a wider roll-out from April 2014.

Organisation: Gateshead Council

Contact: Keith Hogan

Email: keithhogan@gateshead.gov.uk

Phone: 0191 433 2455

Summary: This is an example of a Citizenship Project for people with learning disabilities. It uses an Asset Based Community Development approach to support people to be more involved in community activities, as an alternative to day centres.

Section 5 – Learning from the Examples

When we started the project, we agreed that Good Practice is about what people themselves and families think, and not what the Department of Health or service providers think. This is what made our project unique.

We already know that people who are “invisible” to their local communities are at the greatest risk of abuse, and that when people have valued roles in their communities this creates a sense of security and increases confidence, not just for people with learning disabilities, but also for the wider community. The six examples that were selected for our Checkers’ visits all provide further proof in large and small ways of these facts.

During this project it became clear that the sharing of good examples can generate huge amounts of enthusiasm, and that a “can-do” attitude can make all the difference to the outcomes of a project. Determination, resilience and stamina are very necessary qualities in people who are aiming for and achieving sustainable outcomes.

From all six examples we visited, it was clear that the key to providing successful, effective services and support is co-production (all stakeholders working together as equal partners from the start). Directly involving people with learning disabilities and wherever possible, family members and friends who know them best, in designing and delivering services, should therefore be a commissioning priority.

We tried to ensure that our Good Practice Project was itself an example of the indicators we used to select the best examples, and we believe we achieved this to a high degree. Throughout the project, self-advocates, family carers, service providers, commissioners, and government officials have worked as equal partners, sharing ideas and taking note of our respective needs and interests.

Perhaps the biggest lesson to take from this project is the understanding that the examples of good practice highlighted here are too often dependent upon the work of particular people who care very much about what happens to the people they serve. These people also need to be supported, nurtured, developed and empowered, in order that they can continue to inspire others and spread their good practice.

We suggest the following recommendations to those who commission and provide services:

1. Local areas should engage openly and directly with all stakeholders, including people who use services and their families, when considering how to use the learning from the examples in this report.
2. These examples should not be seen as end goals for good practice, but should be used as reference and inspiration in local areas, with a view to adapting and improving upon them continuously.
3. When developing new services, local areas should build links wherever possible with their neighbours and share ideas, to avoid re-inventing wheels, to learn faster about what works and what doesn't, and to pool resources if this will improve sustainability and maintain quality.

Appendix A

From Norman Lamb MP
Minister of State for Care and Support

Ref: POC3000729846



To: PCT Cluster Chief Executives
Directors of Adult Social Services

Richmond House
79 Whitehall
London
SW1A 2NS

CC: Strategic Health Authority Learning Disabilities Leads
Local Government Association
Association of Adult Social Services
National Valuing Families Forum
National Forum of People with Learning Disabilities

Telephone: 020 7210 3000

Gateway Reference number: 18246
ROCR Approval: pending

Dear Colleague,

12 NOV 2012

**DH REVIEW: WINTERBOURNE VIEW HOSPITAL -
GOOD PRACTICE PROJECT 'WHAT DOES GOOD LOOK LIKE?'**

You will be aware that the Department of Health interim report of the Review on Winterbourne View Hospital was published on 25 June 2012 with the final report due for publication this autumn.

The Department's review brings together information from a range of reviews and investigations including the programme of focused inspections of learning disability hospitals recently completed by the CQC, the NHS South of England review, and the Winterbourne View Serious Case Review.

We are determined to see services that deliver the right model of care and better outcomes for people with learning disabilities and/or autism and behaviour which challenges. The Department alongside the Association of Directors of Adult Social Services, the NHS Commissioning Board, the Local Government Association, the NHS Confederation, Royal Colleges, the Housing and Support Alliance and other partners are committed to working together to this end.

Local authorities and NHS bodies need to develop services that make best use of their existing funding and work in partnership across health and social care. The focus must be on personalised care around the identified needs of each individual, and recognition locally that placing people in services out of area, or in assessment and treatment units longer than is clinically indicated, is not the answer.

Changing commissioning behaviour and developing responsive services within the local community will require real leadership at a local level. My purpose in writing to you is to seek your help with one of the actions coming out of the interim report to:



'Improve the quality of services which empower people with learning disabilities and their families to have choice and control'

This is a good practice project, which the National Valuing Families Forum will lead, working with the National Forum of People with Learning Disabilities, the LGA, ADASS and the NHS.

Work has already started to scope the project around five indicators shown in the interim report. These are:

- (1) **Co-production** – involving people who use service in designing and planning them;
- (2) **Community building** – moving towards community-based support;
- (3) **A capabilities approach to disability** – looking at people's strengths and promoting what they can do;
- (4) **Integrated services** – covering health, care, housing and leisure; and
- (5) **Personalisation** - as a foundation on which other strategies build.

Whilst the focus is on local authorities, we also want to reflect good practice in integrated working with the NHS for people with learning disabilities. We want to know 'what good looks like' and share this with people with learning disabilities and family carers, councils, organisations in the new health and care system and stakeholders.

I very much hope that you will take part in this innovative project. The good practice examples we receive will be used in one of the following ways:

- (i) as a formal presentation at a finishing seminar which I will host with the NVFF and National Forum (we hope those involved in the work locally will attend to present also) following a visit by a Forum member and a member of the Steering Group for the project. The details of the good practice example will also be published in a project report;
- (ii) with further details gathered by phone or email by DH working with the two fora and published in the project report;
- (iii) short details, as provided by you in response to this letter, published in the project report.

The attached framework describes the details we are looking for. It would be helpful if you could confirm at this stage that you are content for all details to be published.



If you would like to take part, can you please return the completed framework to: goodpracticeproject@dh.gsi.gov.uk by **noon on 13 December 2012**. Any queries about the project or this letter should be addressed to: **Pam Nixon, Learning Disability Policy Lead, Department of Health**, pam.nixon@dh.gsi.gov.uk tel: 0207 972 4901.

I look forward to hearing from you.

Best wishes,



NORMAN LAMB

Appendix B – Good Practice Project: ‘What Does Good Look Like?’ – Framework

Please complete a separate sheet for each example you are providing

<p>Name of local authority/health body</p>	
<p>Area/Region</p>	
<p>Broad description of work</p> <p>(include the ways in which it is innovative and how it was developed and your learning from it)</p> <p>You can attach further documentation/ details</p>	
<p>Which Indicator(s) does your example demonstrate and how (see 1 – 5 below)</p> <p>This can be more than one.</p>	
<p>In what way does this example show What Good Looks Like?</p>	

<p>Explain how this work maintains or improves outcomes or access to services</p>	
<p>How have the following been actively involved in the example?</p> <p>a) people with learning disabilities</p> <p>b) family carers</p> <p>c) advocates</p>	
<p>Main contact details (name, position, email and phone) for further details or to arrange a visit.</p>	
<p>Are you content for the details of the example(s) provided to be published by DH?</p>	
<p>IMPORTANT: Please provide an easy read summary (maximum of two sides of A4 in 14 Font) of the example that can be understood by people with learning disabilities.</p>	

Indicators

- (1) **Co-production** – involving people who use service in designing and planning them;
- (2) **Community building** – and moving towards community based support;
- (3) **A capabilities approach to disability** – looking at people’s strengths and promoting what they can do;
- (4) **Integrated services** – covering health, care housing and leisure; and
- (5) **Personalisation** – as a foundation on which other strategies build.

Can you please return the completed framework including your 2 page summary easy read to: goodpracticeproject@dh.gsi.gov.uk by noon on **13 December 2012**. Any queries about the project or this letter should be addressed to: **Pam Nixon, Learning Disability Policy Lead, Department of Health**, pam.nixon@dh.gsi.gov.uk

Appendix C – Questions for Checkers' Visits

 <p>Date of Visit:</p>	
 <p>Where is the Visit?</p>	
 <p>Who are the Checkers?</p>	
 <p>Can we take photos of the people who use the support or service? (Or just the place we visit?)</p>	<p>People who give their permission for photos</p> <p>Names/Signatures:</p> <p>Site only:</p>

	<p>Who is telling us about this example of Good Practice?</p>
	<p>Names:</p>
	<p>How are people who use services, family carers, and the wider community, involved in making it work?</p>

	Setting up the service or support What things were easy to do?
	(Empty space for response)
	And what was harder to do?
	(Empty space for response)
	In the future, how will this example of good practice keep going?
	(Empty space for response)

Turn over for more questions...

	How can the ideas be shared with other providers, so that more people have good lives?
	(Empty space for response)
	Do people who use the support or service, their families, and commissioners think that it gives good value for money?
	(Empty space for response)

	<p>Could the example be presented at an event in the Autumn?</p>
	<p>If yes, please give details of who could do this:</p>
	<p>Names:</p>
	<p>Anything else – comments from staff or people using the service, or replies to other questions that checkers have asked?</p>

Please type up your comments and email your completed visit sheet to:

Jo@inclusioneast.co.uk copy to goodpracticeproject@dh.gsi.gov.uk

Many thanks for your time and support for this project

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