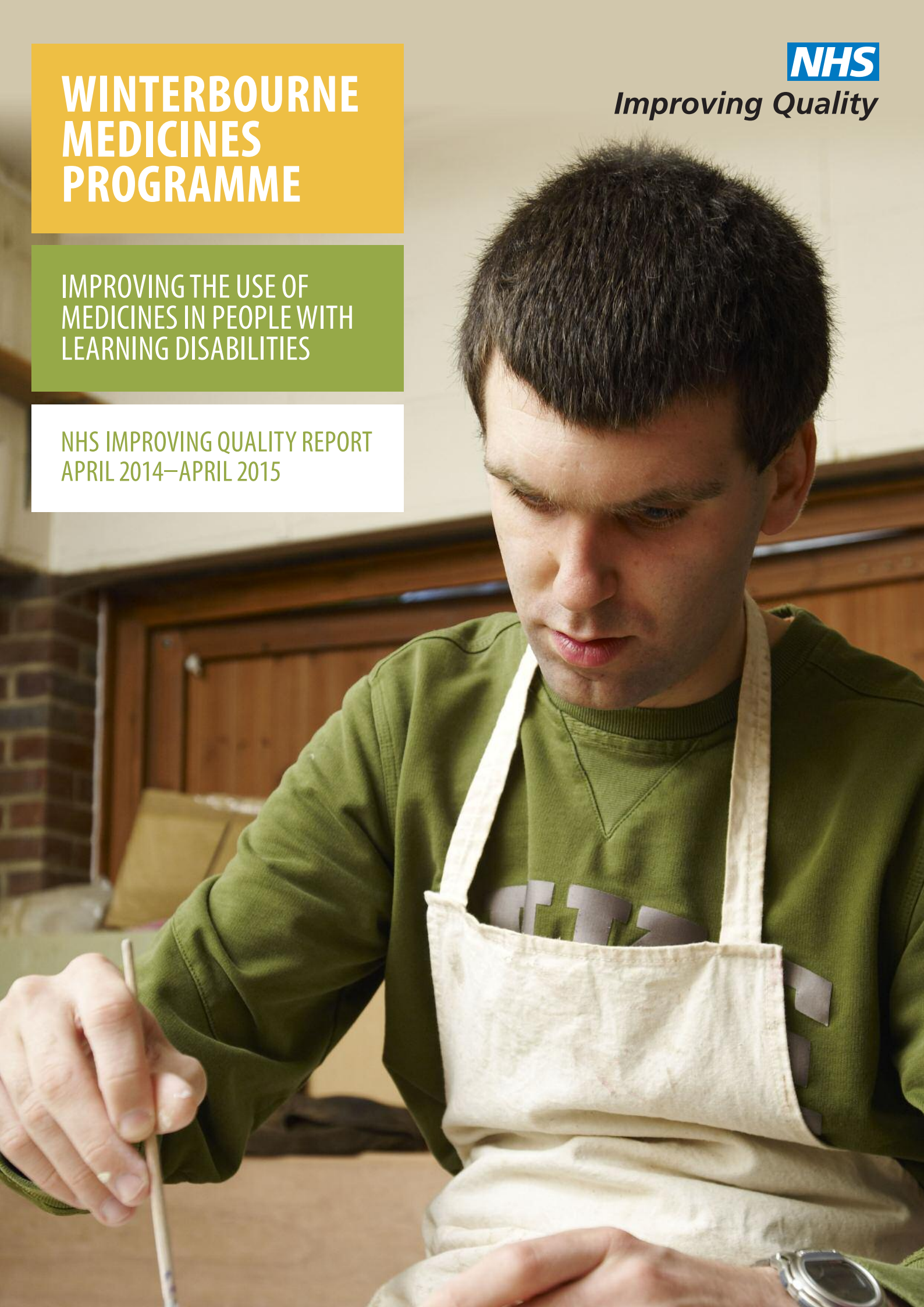
WINTERBOURNE MEDICINES PROGRAMME

IMPROVING THE USE OF MEDICINES IN PEOPLE WITH LEARNING DISABILITIES

NHS IMPROVING QUALITY REPORT
APRIL 2014–APRIL 2015

NHS
Improving Quality



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FOREWORD

Patients and the public expect health services to be high quality – safe, effective and a good experience. The appalling care and treatment of people at Winterbourne View, to say the least, did not meet that expectation. Amongst the many concerns was the inappropriate use of certain medicines. In particular, powerful medicines like antipsychotics. Used well and appropriately, these medicines have a place in clinical care. Used poorly and inappropriately, they can take the form of a restraint or "chemical cosh". That's why I was asked to bring together patient representatives, health professionals, commissioners, policy makers and others to form a consensus of action needed to improve the use of not just antipsychotics in patients with learning difficulty, but also antidepressants, anxiolytics and antiepileptics too.

The consensus was that we should commission three pieces of work to determine how well these powerful medicines are used for people with learning difficulties:

- A detailed examination of data about the use of these medicines in primary care
- An audit of Second Opinion Authorised Doctor decisions about use of these medicines in patients with learning difficulty detained under the Mental Health Act
- A collaborative improvement programme at local level to obtain an in depth understanding of medicines use and to test new ways of working.

This report is about the final element of this programme of work. It is the results of work at six sites caring for people with learning disabilities and observations in numerous settings. I would like to thank the patients and staff of these sites for being so open and willing to learn and improve. I would also like to thank the experts from NHS Improving Quality who guided the sites through the work. There was also great interest from many other sites who wanted to be part of the programme and I hope they too will learn from the results of this work. I am also grateful to the project board which oversaw the programme. In particular I would like to thank David Jack, whose son has learning disabilities. David's family experiences were invaluable in guiding the work.

We know that optimal medicines use should be patient focused and outcome based. It should be safe, effective and evidence based. A patient and their clinician should decide and choose together which medicines to use, or indeed whether to use any medicines at all. Clinicians and patients should routinely monitor and review the medicines they are using. These principles should apply to all patients and to all settings, including inpatients with learning disability.

The three pieces of work identified by the consensus and the next steps are being published which will facilitate action to be taken to optimise medication and ultimately improve the lives of people with learning disability.

Dr Keith Ridge CBE
NHS England – Chief Pharmaceutical Officer

INTRODUCTION

The devastating scandal at Winterbourne View hospital triggered a wide review of care across England for people with Learning disabilities and behaviour that can challenge.

In December 2012, the Department of Health publication "Transforming care: A national response to Winterbourne View Hospital" stated that:

> 7.31 We have heard deep concerns about over-use of antipsychotic and antidepressant medicines. Health professionals caring for people with learning disabilities should assess and keep under review the medicines requirements for each individual patient to determine the best course of action for that patient, taking into account the views of the person wherever possible and their family and/or carer(s). Services should have systems and policies in place to ensure that this is done safely and in a timely manner and should carry out regular audits of medication prescribing and management, involving pharmacists, doctors and nurses."

To investigate these deep concerns, Dr Keith Ridge (NHS England - Chief Pharmaceutical Officer) commissioned NHS Improving Quality to support the work. A reference group of key stakeholders was brought together and a Winterbourne Medicines Programme Board was set up to work in partnership to understand the use of medication for people who have a learning disability and behaviour that can challenge.

The Winterbourne Medicines Programme was officially launched in April 2014 and three initiatives ran in parallel to support the programme:

- NHS Improving Quality worked in collaboration with project sites to understand and improve services
- The Care Quality Commission audited medication data relating to the "Second Opinion Authorised Doctor" (SOAD) requirement
- Public health experts examined the use of antipsychotic, antidepressant, anxiolytic, hypnotics and anticonvulsants in primary care through the use of the Clinical Practice Data Link database (held by Healthcare Products Regulatory Agency (MHRA)).

WINTERBOURNE MEDICINES PROGRAMME – NHS IMPROVING QUALITY

The Winterbourne Medicines Programme Board consisted of the following members:

Keith Ridge	Chief Pharmaceutical Officer	NHS England
Joanne McDonnell	Senior Nurse for Mental Health & Learning Disabilities	NHS England
David Jack	Parent & Carer Representative	n/a
Zoë Lord	Improvement Manager	NHS Improving Quality
Carol Marley	Improvement Manager	NHS Improving Quality
Anabela De Gouveia	Programme Coordinator	NHS Improving Quality
Angela Hassiotis	Professor of Psychiatry of Intellectual Disability, University College London	Camden Learning Disability Service and University College London
Christopher Cox	Learning Disability Policy & Programmes Lead	Department of Health
Gyles Glover	Co-Director, Learning Disabilities Team	Public Health England
Ray Avery (Member until August 2014)	Partnership Manager	NHS England
Sarah Bernard	Consultant Psychiatrist	SLAM (South London and Maudsley NHS Foundation Trust)

The programme of work was shaped by key stakeholders who attended reference group meetings and by the Winterbourne Medicines Programme Board. A **Project Initiation Document** was approved by Keith Ridge (NHS England – Chief Pharmaceutical Officer), Fiona Thow (NHS Improving Quality – Interim Head of Programme), and Juliet Beale (NHS England Director of Nursing: Quality Improvement and Care).

The programme aspiration was to ensure safe, appropriate and optimised use of medication for people with learning disabilities whose behaviour can challenge.

The scope of the work included children, young people and adults who live at home, in the community, care homes, hospitals, assessment and treatment centres, schools, secure settings, prison and in custody.

The programme had these six objectives:

1. To ensure the service user is central to the work
2. To review and develop a deep understanding of issues around current medication processes
3. To identify and share notable practice
4. To identify a method of measuring change and improvement
5. To test new ways of working to improve processes across the pathway - where appropriate
6. To improve awareness of the issues around medication.

To deliver these objectives, NHS Improving Quality worked collaboratively with project sites, talked to professional bodies, charities, individuals with learning disabilities, carers, other people working to achieve recommendations from the Winterbourne Concordat, key stakeholders and front line staff. Visits to numerous other services in different settings also took place to fully understand key issues.


GOAL
GRAZIOLI GIOCHI

"MEDICINES SHOULD BE EVERYONE'S BUSINESS."

PARENT, STAFFORDSHIRE

PROJECT SITES

In May 2014, the programme invited organisations to submit expressions of interest to work with NHS Improving Quality for six months, to get a deep understanding of current practices and test new ways of working.

Within a very short timeframe, there was a high demand for more information about this work and 54 expressions of interest received. This was a significant indication that there was support for change and improvement within the clinical community. The majority of applications came from adult NHS care providers with very few from children and young people's services and the private sector. There were no submissions from prisons, the justice service or schools.

The selection process ensured that the successful sites reflected different parts of the care pathway and covered a range of inpatient and community services for children, young people and adults. The following six sites were chosen to work in partnership with the team at NHS Improving Quality:

- **Devon Partnership NHS Trust**
- **Cheshire and Wirral Partnership NHS Foundation Trust**
- **Hertfordshire Partnership University NHS Foundation Trust**
- **Northumberland, Tyne and Wear NHS Foundation Trust**
- **South West London and St George's Mental Health NHS Trust**
- **Sussex Partnership NHS Foundation Trust.**

Community of practice

Following the significant interest in the programme of work, an online community of practice was developed to instigate a network that would capture the energy for change, support sharing and learning. The community of practice, in partnership with NHS England 6C's website is wider than the scope of the Winterbourne Medicines Programme and is for anyone interested in improving the lives of people with learning disabilities. The website is for sharing information, guidelines, research papers, notable practice, case studies, blogs and has a forum to pose questions. The community can be accessed via **this link** and by joining the learning disability community.

Support given to project sites

Each site received bespoke support to use quality improvement tools and techniques in order to understand the current services they provide and to test new ways of working. The support was provided through a variety of approaches over a six month period including site visits, conference calls, meetings and events.

Project sites committed to a systematic project management process to ensure learning was captured and progress monitored. This process included:

- Memorandum of understanding – signed by their executive sponsor
- Project plan
- Measurement plan

- Communication plan
- Monthly highlight report
- Case studies
- Final report.

Project launch

The project sites were officially announced at a national stakeholder event in September 2014. The event brought together the project site teams, experts by experience, families, key stakeholders and experts in the field of learning disabilities and medicines. Project teams included clinical leads, psychiatrists, commissioning leads, nurses, managers, therapists, psychologists, pharmacists and a medical director. The event set the scene by highlighting the current national programme of work and future vision for learning disabilities and medicines. The sites presented their project proposals and gained advice from peers and experts. Delegates participated in an interactive quality improvement workshop to provide them with basic knowledge to commence their service improvement journey. The quality improvement workshop included:

- Top tips for starting your project
- Model for Improvement
- NHS Change Model
- How to meaningfully involve patients and their families
- Understanding the patient journey with process mapping
- Measuring for improvement
- Root cause analysis & pareto charts
- Plan do study act (PDSA) cycles
- Understanding the process and variation using statistical process control
- Understanding human dimensions of change.

PROJECT SITE OVERVIEW

Devon Partnership NHS Trust

Devon Partnership NHS Trust provides mental health and learning disability services for people in Devon. The learning disability community team which helps to support adults with a learning disability to live in the community, set out to ensure specialist pharmacy knowledge and expertise was fully incorporated into the multidisciplinary team. With this in place, it was expected that services and the skills within the wider team would be enhanced.

Project work included:

- Optimising the safe and appropriate use of medications for people referred to the service by introducing new medication related processes and improving medication knowledge with the multidisciplinary team
- Development of a tool to support the completion of medicine reconciliation at the point of referral
- Development of a Pharmacy Triage Tool to proactively target medication reviews
- Involving people with learning disabilities, their families and carers in the service development
- Ensuring service-users and their supporters have access to appropriate information about medication
- Promoting awareness and increasing knowledge of the multi-professional team about medication (including Community Pharmacists and General Practitioners (GPs)).

A detailed case study of the work achieved at Devon Partnership NHS Trust can be found **here**.

Cheshire and Wirral Partnership NHS Foundation Trust

Cheshire and Wirral Partnership NHS Foundation Trust provides inpatient and community mental health services as well as learning disability services and drug and alcohol services across Cheshire and Wirral.

To ensure a high quality standard of care for people with learning disabilities and behaviour that can challenge, the learning disability team had developed a pathway to address the needs of patients. The pathway included medication processes and by following the quality standards described in the pathway, the quality of clinical care for this group of patients would be maximised and variation reduced. This project audited adherence to the pathway, identified and implemented areas for improvement to ensure all medicines are prescribed safely and people receive optimal care.

Project work included:

- Undertaking a full analysis of the clinical pathway to ensure all medicines are prescribed in a safe and optimised manner
- Listening to the experiences of patients and carers through the development of service user stories to inform the work. Access the case study **here**
- Developing an aide memoire for clinicians in relation to medication optimisation
- Commenced an implementation plan based on the results of the audit.

A detailed case study of the work achieved at Cheshire and Wirral Partnership NHS Foundation Trust can be found **here**.

Hertfordshire Partnership University NHS Foundation Trust

Hertfordshire Partnership University NHS Foundation Trust provides health and social care for people with mental ill health, physical ill health and those with a learning disability.

The community learning disability services in North Essex became involved in the Winterbourne Medicines Programme with the aspiration that medication is used as a last resort and only after other non-pharmacological methods of intervention are utilised when treating people with behaviours that may challenge.

Project work included:

- An audit highlighting an overreliance on medication to manage people without co morbid mental illness that showed variation in practice with regards to the use of functional analysis
- Development of a pathway for behaviour that may challenge
- A series of process maps and data that highlighted slow and complex referral systems
- Addition of the challenging behaviours pathway to the electronic patient record
- Introduction of the Brief Functional Assessment (BFA) and a Motivational Assessment Tool for the behaviour assessment phase of the pathway.
- Development of a simple prescribing practice check list for psychiatrists to use in the outpatient clinics
- Development of a standard letter to all GP's in North Essex to raise awareness of medication issues and the need to rule out physical health issues when presented with people who are exhibiting behaviours that may challenge.

A detailed case study of the work achieved at Hertfordshire Partnership University NHS Foundation Trust can be found **here**.

Northumberland, Tyne and Wear NHS Foundation Trust

Northumberland, Tyne and Wear NHS Foundation Trust provides a range of services for people with learning disabilities, their families and care providers in inpatient and community settings.

The Trust had embarked on a major transformation of community services which had been mapped and redesigned through large scale engagement with clinicians, partners, service users and carers. The Trust was in the process of developing a challenging behaviours pathway in relation to using positive behaviour support and this project gave the opportunity to incorporate prescribing to this pathway and the development of best practice guidelines.

Project work included:

- Literature review carried out to establish best clinical practice for prescribing
- Questionnaire developed to gain patient and carer feedback about their experiences with psychotropic medicines
- Audit of prescribing practices in the assessment and treatment centre and for people living in the community

- Development of good practice guidelines in progress using a multi-disciplinary approach which includes:
  - Learning disabilities psychiatry
  - Nurses
  - Positive behaviour support practitioners
  - Newcastle and North Tyneside Clinical Commissioning Groups
  - Pharmacy
  - Local authority
  - Speech and language
  - Psychology
  - Primary care
- Future plans include training for staff to support the implementation of the guidelines along with a regular audit of adherence
- The work will be spread across other areas of the Trust with an emphasis on involvement of GP practices.

A detailed case study of the work achieved at Northumberland, Tyne and Wear NHS Foundation Trust can be found **here**.

South West London and St George's Mental Health NHS Trust

Wandsworth Child and Adolescent Mental Health Services (CAMHS) Learning Disability Team is a Tier 3 service for children and young people up to the age of 18, who have a GP within the Wandsworth Borough and who have moderate to profound learning disability and additional mental health or behavioural needs.

The community learning disability team worked closely with parents and carers to gain a greater understanding of the issues around current medication processes, for children and adolescents with a diagnosis of moderate to severe intellectual disability presenting with behaviours that may challenge.

Project work included:

- Development of the parent/carer forum
- Introduction of a full booking service for new referrals
- A template for referral to psychiatry to ensure all team members have considered and implemented other approaches before medication
- Baseline data collected by a case note review of the current prescribing and medication monitoring practices. This information is now collected for all patients as part of an ongoing process
- Development of a template for safe and timely medications monitoring, including a physical health monitoring booklet
- A telephone review clinic for early contact with patients, parents and carers after initiation of medication
- Direct access to pathology laboratory for blood results to aid medication review

- Parents and carers helped shape the information they required about the service at the first appointment and how the interventions offered by the service could be explained to them better
- User involvement was and still is an integral part of this project. Parents and carers involved in the mapping of the service and the setting up of a parent/carer forum have ensured that any changes made to the service are in the best interests of the users
- The multi professional team have worked with their local pharmacists and Prescribing Observatory for Mental Health (POMH) UK audit leads to develop joined up working for developing and implementing processes for children's medication monitoring Trust wide.

A detailed case study of the work achieved at South West London and St George's Mental Health Trust can be found **here**.

Sussex Partnership NHS Foundation Trust

Sussex Partnership NHS Foundation Trust provides specialist health services to people with a learning disability across Sussex. These services include a range of community and inpatient services, including positive behaviour support teams delivered jointly with local authorities.

The Selden Centre was part of this programme of work and is a 10 bedded inpatient service for adults with a learning disability. The service provides an integrated model of care, delivered by the interdisciplinary team which includes speech & language therapy, occupational therapy, nursing, psychiatry, pharmacy and clinical psychology.

Project work included:

- Understanding the current process by completing a baseline process map for medicines management, looking at pre-admission, admission and discharge processes. Data from the national NHS Learning Disability Census 2014 was also used as part of the baseline for the improvement work
- Developing accessible resources to support clients and carers understanding about medication choices, side effects and management
- Developing two versions of a 'My medicines pack' to support the client and carer on discharge
- Developing an easy read version of Glasgow Antipsychotic Side-effect Scale (GASS) to facilitate discussion about side effects of medication
- Establishing new systems to inform prescribing. This includes gaining a detailed history of previous prescribing, current medicines and the impact of these medicines. Tools include standard work letters, observations and questions, templates and audit checks
- Improving the rigour behind the use of and monitoring of 'as required medication' (PRN) medication including rapid tranquilisation.

A detailed case study of the work achieved at Sussex Partnership NHS Foundation Trust can be found **here**.

Resources

The following resources (which include, pathways, templates, case studies and tools) have been developed by the six sites and can be accessed via the community of practice and via the case studies on the previous pages:

- Challenging Behaviour Pathways
- Triage tool to involve clinical pharmacists in medication reviews
- Audit template to understand current practice
- Audit template to capture clinical case load
- Templates for GP referrals
- Case study and tool to effectively monitor the use of as required (PRN) medications
- Template for medication monitoring
- Case study to reduce referral to first appointment
- Case study to set up a patient/carer forum
- Information leaflet for the use of off-licence medication
- Easy read information about medication
- Check-list for psychiatrists prior to prescribing
- Aide memoire for prescribing
- Medication questionnaire for inpatient assessment and treatment centre
- Medication feedback questionnaire for service users.

OBSERVATIONS AND KEY LEARNING POINTS

The observations and key learning points from this programme of work have arisen from the project sites, other service providers, clinical staff, experts in the field, people with learning disabilities, families and carers.

Within the learning disability community, it is acknowledged that there are many areas for improvement, where medicines can be optimised to improve people's lives. There are good services available for people with learning disabilities, however this is not the case for everyone and there is tremendous variation in practice. Steps can be taken to reduce this variation through acknowledgement, identification, sharing and spread of notable practice.

The observations within this section were not isolated incidents; they were seen in numerous services and/or verified by clinical staff across the country. The observations and associated key learning points have been categorised under the following themes:

1. The need to understand the pressures and reasons for prescribing
2. The importance of sharing up-to-date and comprehensive information
3. The significance of understanding the current medication processes
4. The value of integrated pathways of care
5. The importance of involving of people with learning disabilities, their families and carers
6. The development of teams, skills and culture.

1

The need to understand the pressures and reasons for prescribing

To fully understand the complexity of the culture and practice behind prescribing, it is imperative that the reasons for prescribing are fully understood.

The following has been observed:

- Medication is sometimes seen as 'the answer', a quick fix, the most easily available and straight forward option
- At times prescribers are pressured to prescribe by a variety of people (including parents, carers, care homes, schools and other professionals). This pressure is applied for a variety of reasons including risks to the service user, others and the possible loss of placement
- Medication is sometimes prescribed because access to alternative therapies that may reduce or mitigate the need for some medication varies across the country (e.g. speech and language, behavioural support).
- Some prescribers were not aware that they should avoid prescribing more than one drug per drug category and therefore multiple prescribing could be seen as common. It was also noted that not everyone involved in the medication processes were aware that anti-psychotic medication is used off-licence to manage behaviour that may challenge
- In a crisis situation, services that are reactive are often reliant on the use of medication and physical restraint. Learning from the project sites shows that having a pathway (which includes a clear process to manage the escalation of behaviours) may avoid restraints being used
- Less than adequate staffing (including the high turnover of unskilled agency staff) has been seen to have a negative impact on safe and appropriate prescribing
- At times there is a lack of clarity of who is accountable for the prescribing – GP or Psychiatrist. In some instances, medication is commenced by a Psychiatrist and then repeat prescriptions continue through the GP without review
- Good practice is when teams understand the underlying causes for the behaviours that challenge and rule out any physical illness before resorting to medication.

"MANY INDIVIDUALS PRESENT BEHAVIOUR DESCRIBED AS CHALLENGING BECAUSE THEIR NEEDS ARE NOT MET BY THOSE WHO SUPPORT THEM. IF THE SUPPORT OFFERED IS INAPPROPRIATE OR INADEQUATE, OFTEN THE PATIENT'S ONLY MEANS OF RESPONDING IS BY PRESENTING BEHAVIOURAL CHALLENGES. ALTHOUGH THE BEHAVIOUR IS UNDESIRABLE AND SOCIALLY UNACCEPTABLE, IT COULD PERHAPS BE CONSIDERED TO BE LEGITIMATE. IN MY EXPERIENCE A PERSON CENTRED APPROACH AND MODEL OF CARE WHICH PROVIDES A SUITABLE ENVIRONMENT CAN VERY OFTEN PREVENT THE NEED TO PRESENT THE DIFFICULT BEHAVIOUR."

PARENT

"TEAMS SHOULD RESPOND TO THE PERSON AND NOT JUST THE BEHAVIOUR – THEY NEED TO FIND THE REASONS BEHIND THE BEHAVIOUR."

PARENT, BUCKINGHAMSHIRE

2

The importance of sharing up-to-date and comprehensive information

To provide high quality care, everyone involved needs to be aware of what is being prescribed, why it is prescribed and there must be robust processes and recording in place. Observations have highlighted variation in services across the country and this high quality of care is not provided everywhere.

Throughout this programme of work, the following have been observed:

Medication history/recording:

- Many staff do not appear to know the original indication for commencing the medication
- Past medication history is not always available and where it is available, it is not always referred to. Key learning from the project sites has highlighted the richness of this history and how it should be used to inform clinical decisions. Learning also shows that where past medication history is not available; families and carers can often provide a coherent long term medication history
- Some providers lack robust recording of the reasons for the administration of 'as required' (PRN) medication. Sussex Partnership Foundation Trust have addressed this issue by introducing a standardised process to ensure medication monitoring has the same rigour as the monitoring of physical restraint. Access the case study here.

Side effects and review:

- Staff in some services do not have the knowledge to recognise medication side effects and therefore unable to clearly and accurately report, record and take appropriate action
- Some patients do not have a timely structured review and repeat prescriptions can be written without face to face consultation with the person involved or their family.

Information leaflets:

- Patients, their family and carers should be given sufficient information about any proposed medication to allow them to make an informed decision. When medications are prescribed or dispensed, basic written information about medicines is not always available in a suitable format (i.e. easy read). A key learning point is that written information should include reasons why the medication has been prescribed, any adverse side effects and what to do if side effects arise. There should also be written information provided if the medication is prescribed off-licence to manage behaviours that may challenge.

DID YOU UNDERSTAND THE PRESCRIBED MEDICATION?

"MEDICATION CARDS ARE SET UP SO THAT WE HAVE CLIENT INFORMATION LEAFLETS WITH THEM ANYWAY, BECAUSE OUR POLICY IS IF YOU ARE GOING TO BE GIVING MEDICATION, YOU SHOULDN'T BE GIVING SOMETHING YOU HAVE NO CONCEPT OF, YOU'VE GOT TO BE AWARE OF THE SIDE EFFECTS TOO. SO WE HAVE INFORMATION LEAFLETS FOR EVERY SINGLE MEDICATION THAT'S PRESCRIBED WITH US."

EXTRACT FROM A CARER INTERVIEW AT CHESHIRE AND WIRRAL PARTNERSHIP NHS FOUNDATION TRUST

ASKED HOW COULD THE EXPERIENCE BE EASIER FOR PEOPLE IN THE FUTURE:

"HAVING IT ALL WRITTEN DOWN, EXPLAINING WHAT THE MEDICATION WOULD DO TO ME WOULD HAVE HELPED ME. MAYBE DO THAT WITH OTHER PEOPLE, STOP THEM WORRYING. THAT WOULD HAVE HELPED ME."

EXTRACT FROM A PATIENT STORY AT CHESHIRE AND WIRRAL PARTNERSHIP NHS FOUNDATION TRUST

"SOMETIMES MY TABLETS ARE CHANGED AND I DON'T KNOW WHY…I DON'T LIKE THE NEW ONE BECAUSE IT MAKES ME SLEEPY."

PATIENT

"WHERE CAPACITY IS A PROBLEM, GOOD QUALITY, DISCIPLINED OBSERVATION OF THE PATIENT, BY THE CARERS IS ESSENTIAL IN ORDER TO PROVIDE ACCURATE FEEDBACK TO THE CLINICAL TEAM. THIS IS VITAL TO FACILITATE GOOD QUALITY CARE."

PARENT OF J

3

The significance of understanding the current medication processes

Quite often, it would appear that assumptions are made around the medication process. Without a true understanding of what actually happens, services cannot be effectively understood, managed or improved. It is evident from observations across the country, that not all service providers or staff within services have a deep understanding of a process or pathway and therefore don't know the basic information like the number of people on their caseloads or know who is being prescribed medication to manage behaviours.

Work from the project sites has revealed how difficult it is to obtain information from computerised systems. In some sites there has been an issue with a clinical code for behaviour that may challenge because it is not a clinical diagnosis and therefore it is not always clear or documented in patient notes. The project sites found that manual data collection was the only way to accurately collect the information they require. Although this was time consuming, they have reaped the benefits of getting a deep understanding of their service.

The project sites also found it extremely useful to conduct a process mapping exercise. The development of these maps ensured everyone involved could understand the current process for prescribing, reviewing and stopping medication. The maps also highlighted current variation in practice between clinical staff and areas for improvement.

"IT'S ONLY FROM BEING PART OF THIS PROJECT THAT BOTH MYSELF AND THE TEAM TRULY UNDERSTAND THE PATHWAY FOR OUR PATIENTS FROM ALL PERSPECTIVES."

PROJECT LEAD – PSYCHIATRIST

4

The value of integrated pathways of care

From observations, it appears that not all services have a clear pathway of care. The project sites have shown that to provide high quality care, it is vital to have a pathway which is integrated across organisational boundaries. There is a need for joined up working and open communication between commissioners of the service, general practice, community services, inpatient services and social services. The pathway should highlight that the use of medicines should be the last resort to control behaviour and a good pathway should involve other management strategies such as positive behaviour support (PBS) with clear guidelines for the management of crisis situations. Learning from Cheshire and Wirral Partnership NHS Foundation Trust highlights the requirement for regular audits to be in place to check adherence to the pathway to ensure every person receives the highest quality of care.

"THERE IS VARIATION IN THE WAY MY COLLEAGUES AND I PRESCRIBE FOR BEHAVIOURS THAT CHALLENGE – THE DEVELOPMENT OF A PATHWAY HAS HELPED US HAVE OPEN AND HONEST CONVERSATIONS ABOUT PRESCRIBING PRACTICES."

QUOTE FROM A PSYCHIATRIST

"I ALWAYS SEEM TO KNOW MORE THAN THE GP – I WISH THEY WOULD TALK TO EACH OTHER!"

PARENT OF JANE,
MANCHESTER

5

The importance of involving people with learning disabilities, their families and carers

A key objective of the Winterbourne Medicines Programme and of each of the project sites was to ensure the service user is central to the work. Each project site involved service users, their families and carers by holding focus groups, one to one meetings or by conducting surveys. By doing this, each site has learnt more about the people taking medicines, the associated medication processes and where improvements can be made.

From listening to individuals, their families and carers, it is evident that there is variation in how much individuals and families feel involved in their care and how much they feel listened to. Through this work, project teams found that service users, families and carers are a rich source of information, especially about past history and previous regimes. When individuals are cared for at a distance from their families and carers, families stressed that they should not be forgotten when decisions about new medication or changes to current medication are made.

Project site teams are also found that individuals, families and carers are best placed to inform providers of the service that is being delivered. The team in Wandsworth involved parents in a process mapping exercise and have set up a parent and carer forum to ensure the services meet the required needs.

"DON'T MAKE ASSUMPTIONS ABOUT WHAT FAMILIES WOULD LIKE–ASK THEM! THE TEAM MADE A NUMBER OF ASSUMPTIONS ABOUT WHAT PARENTS CARERS WOULD LIKE, ALL OF WHICH TURNED OUT TO BE WRONG. WITH MANY COLLECTIVE YEARS OF EXPERIENCE WORKING WITH FAMILIES THIS CAME AS A BIT OF A SHOCK, BUT WAS ALSO IMPORTANT LEARNING FOR TEAM MEMBERS. WE ALSO DISCOVERED THAT PARENT CARERS READILY UNDERSTOOD RESOURCE CONSTRAINTS AND WERE OPEN TO THE MOST APPROPRIATE AND EFFICIENT USE OF THE RESOURCES THAT WE HAVE."

PSYCHIATRIST IN WANDSWORTH

"BEFORE THE APPOINTMENT DID YOU KNOW WHAT TO EXPECT?

YES, TO BE FAIR THEY ARE QUITE GOOD WHEN THEY SEND LETTERS OUT, THEY TELL US IF WE NEED TO BRING ANYTHING – STAFF SHOWED ME AN EASY READ LETTER ABOUT WHEN AND WHERE THE APPOINTMENT WAS."

EXTRACT FROM A CARER INTERVIEW

6

The development of teams, skills and culture

Multidisciplinary/interdisciplinary teams:

Observations within inpatient and community settings has highlighted that minimal clinical pharmacy expertise is involved to support prescribing and medication reviews. The project work from Devon Partnership Trust **(case study)** and Sussex Partnership NHS Foundation Trust **(case study)** clearly highlights the advantages of involving a clinical pharmacist in the multidisciplinary team for the patient and clinical staff.

> **"IT'S GREAT TO HAVE THE PHARMACIST IN THE MDT MEETINGS AS YOU CAN ASK THERE AND THEN ABOUT SIDE EFFECTS AND GET A REALLY HELPFUL ANSWER."**
>
> CARER IN SUSSEX

Families and clinical staff have informed the programme that when there is a lack of continuity of teams caring for individuals, there appears to be an increased use of medication. This is important information for managers and care staff to be aware of and take appropriate action where necessary.

Improvement skills:

Observations from services across the country highlighted minimal levels of quality improvement knowledge and expertise to provide the continuous improvement of services. These improvement tools and techniques can empower everyone involved to take positive steps in commencing a continuous improvement journey to understand current services, test and implement changes that can enable safer high quality care. NHS Improving Quality has provided the project site teams with quality improvement training and has also supported teams to implement the tools and techniques within their service.

An introduction to quality improvement tools and techniques can be found in **"First steps to quality improvement: A simple guide to improving services."**

"I THOROUGHLY ENJOYED THE WHOLE THING AND THINK IT WENT REALLY WELL. LOTS OF PARTICIPATION AND ENGAGEMENT, AND LASHINGS OF ENTHUSIASM FOR QUALITY IMPROVEMENT HAS COME FROM IT, THERE IS NO DOUBT! GREAT STUFF!"

COMMENT FROM COMMUNITY HEALTH SERVICE MANAGER FOLLOWING QUALITY IMPROVEMENT TRAINING

Culture

Observations from reviewing pathways of care across the country highlighted an apparent culture not to challenge prescribing decisions. This has been witnessed between GP's and Psychiatrists and also between Psychiatrists and members of their own clinical teams. Organisations should encourage the presence of a positive and supportive learning culture to enhance high quality safe care for service users and for a stronger workforce.

"ALL STAFF SHOULD BE ABLE TO SPEAK UP – NO MATTER WHAT BAND THEY ARE."

NURSE – KENT

" I HAVE TWO SONS AGED 14 AND 6 THEY BOTH HAVE LEARNING DISABILITIES. AT EVERY APPOINTMENT THEY TRY TO OFFER US MEDICATION. YES THEY CAN BE CHALLENGING, BUT SO CAN ALL KIDS."

PARENT – YORK

PEOPLE WITH LEARNING DISABILITIES DESERVE SAFE HIGH QUALITY CARE

CONCLUSIONS AND RECOMMENDATIONS

This programme of work provides a deep understanding of the use of medication for people with learning disabilities and behaviours that challenge. The programme has also tested and implemented new ways of working so that people's lives have been improved and will continue to be improved by the reduction of unnecessary prescribing of psychotropic medications.

The significant level of interest throughout the entire programme of work has been remarkable, and this highlights the recognition that change is required and the readiness of the learning disability community for change and improvement.

While some people's medications are optimised, it is evident from the 'observations and key learning' section of this report, that further work is required across the board to ensure all people with learning disabilities and their families receive the same high standard of care so they can have the best possible quality of life.

It is important that all of the observations and key learning points are addressed; however, there are six key recommendations posed, that when addressed, will maximise improvement outcomes.

Recommendation 1: Involve people with learning disabilities, their families and carers

The statement "no decision about me, without me" should be made a reality across the patient pathway: in primary care, before a diagnosis, at referral and continue after a diagnosis. Everyone providing care should ensure that the person with learning disabilities, their family and carers are treated as partners, are actively listened to, encouraged and supported.

Service users, their families and carers should be utilised as they are often best placed to provide rich information about the services provided, what it is like to use the services, where improvements can be made and specific medication matters like a comprehensive long term medication history.

Work from the project sites has shown that continuous patient and carer involvement, using meetings, forums and surveys, has highlighted areas for improvements that can improve quality of life and care.

Recommendation 2: Invest in quality improvement training and time-out

An essential requirement to achieve high quality safe services is having staff who are equipped with the knowledge of quality improvement along with protected time-out to practically apply the continuous improvement techniques. The skills will enable a systematic (rather than ad-hoc) approach and will aid sustainable improvement.

The project sites received quality improvement training and invested time to understand and practically improve their services. This was valuable learning for the teams and it is evident that improvements to services have been made and will continue.

Recommendation 3: Undertake analysis to understand current practice and areas for improvement

There is a responsibility of people working within learning disability services to take stock of their practice and the services they provide. Analysis can be undertaken in a number of ways including data collection, audits, process mapping and talking to staff and service users. This analysis will provide a clear baseline from which to understand and then improve services. Key areas would be to understand the number of people on the caseload, the extent of polypharmacy, the documented diagnosis related to the prescribing, the difference between current practice and a written pathway and do service users receive written information in a suitable format?

By obtaining data and reviewing current services, the six project sites found many areas where they could make small and large scale changes to improve quality and safety.

Recommendation 4: Ensure services actively use a care pathway for behaviours that challenge

To ensure everyone receives continuous high quality and safe care, it is imperative to have an integrated care pathway which is followed by a multidisciplinary team. Within this pathway the safe and appropriate use and review of medicines should be clearly defined. If pathways are not in place or if they are not followed, patients are at risk of not receiving the highest quality of care due to variation in practice. Project sites have benefited from implementing pathways of care and have also identified the requirements for regular checks to be in place to ensure adherence to the pathways.

Recommendation 5: Employ multidisciplinary / interdisciplinary approaches

Clinicians need to work within a multidisciplinary team. This approach is essential in providing a holistic view and comprehensive management of behaviours that may challenge. A team approach to assessment, care planning and review should address the available options and (where possible) these should be implemented before commencing medication. Work from the project sites has highlighted the immense benefits of involving clinical pharmacists within the multidisciplinary team.

Recommendation 6: Stop and check at every stage

At every point along the pathway of care there is a responsibility from everyone involved to 'stop and check' that the medicines and the care is appropriate and delivered at safe high quality standard for the user of the service. The service users, parents, families and their carers should also be given the opportunity to 'stop and check' and be provided with appropriate information about the service, treatment options and medication.

Every time a prescription is written, requested or when reviews take place are all good opportunities to 'stop and check'. At this point questions should be asked: Is the medication still required? When can the medication be reduced and/or stopped? Are there other interventions?

People with learning disabilities should receive safe high quality care. Therefore, it is vital that the learning and recommendations from this programme of work are taken forward by individuals and organisations.

This work should also be used as the foundation for an ongoing programme of action led by NHS England to optimise use of medication in people with learning disabilities and behaviour that may challenge. An approach similar to the 'call to action on the use of antipsychotic drugs for people with dementia' could be used to stimulate widespread change. The approached used for the Call to Action for Dementia used the theory and core principles from social movements, community organising, service improvement and organisational development to capture hearts and minds, to build capacity through commitment with practical skills.

Across the country, there is a great deal of variation within learning disability services and this does not provide the necessary high quality optimised care for everyone. However, improvements are being made, good practice is starting to be spread and there is a real passion to achieve excellence and improve people's lives. This needs to continue at pace to ensure everyone can lead better lives and have great experiences of care.

"SINCE COMING OFF TABLETS WE HAVE SEEN LOTS OF POSITIVE CHANGES. HE IS MORE COMMUNICATIVE AND IS ABLE TO PROBLEM SOLVE IN A MUCH BETTER WAY."

PARENT

"SINCE HAVING THE RIGHT TABLETS *XXX* IS A DIFFERENT PERSON. HE IS NOT ANGRY, STOPPED SELF-HARMING, DOES NOT HIT OTHERS, IS ABLE TO GO OUT, DEALS WITH NOISES BETTER AND IS SUCH A PLEASURE TO WORK WITH."

PARENT

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