



Joint review report

Commissioning services and support for people with learning disabilities and complex needs

Name of council	Gateshead Council
Name of primary care trust(s)	Gateshead PCT
Area	North
Month and year of visit	November 2008

Commission for Social Care Inspection

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The Mental Health Act Commission provides a safeguard for people who are detained in hospital under the powers of the Mental Health Act.

Background

We wanted to place people with learning disabilities and complex needs and family carers at the heart of this joint commissioning review.

A reference group was established that included people with learning disabilities, family carers and commissioners to ensure our methodology focused on the concerns of people with learning disabilities and complex needs.

The methodology was developed for the commissioning process for people with learning disabilities and complex needs. We wanted to understand the impact of commissioning processes from their perspective. To do this we:

- Spent time with people with learning disabilities and complex needs, which we called 'A Day in the Life of...' to understand the outcomes for people.
- Carried out mystery shopping exercises to see how far local services met individuals' needs.
- Held sessions open to the public so that we heard a wide range of views from the community.
- Held individual interviews and focus groups.
- Looked for examples of good practice that we could report, enabling others to learn and improve their commissioning practices.

The review team combined people with learning disabilities and family carers and 'peer review' commissioners as team members enabling us to focus directly on what matters to people with learning disabilities and complex needs.

(For further information on the methodology please refer to the Appendix.)

The commissioning of services and support for people with learning disabilities and complex needs

Gateshead Council and Gateshead PCT

November 2008

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The joint review of commissioning services and support for people with learning disabilities and complex needs

Report

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Introduction

A review team visited Gateshead during November 2008 to find out how well the council and PCT were commissioning services and support for people with learning disabilities and complex needs.

This report sets out, for the commissioning organisations, the findings from the review, with a summary and recommendations for action. It is also intended to be of interest to the general public, and in particular, for people who use services in Gateshead. It will support the council and PCT and their partner organisations in Gateshead in working together to improve the lives of people with learning disabilities and complex needs.

Local context

Gateshead is a town in Tyne and Wear, North East England. The town of Gateshead lies on the southern bank of the River Tyne. Its town centre is very close to Newcastle city centre and together they form the urban core of Tyneside. It is the main conurbation in the Metropolitan Borough of Gateshead.

Information from the 2001 census is that the population of Gateshead is just over 196,000. Of this figure just under 150,000 are people over the age of 18. Using the national prevalence rates for the numbers of people with a learning disability it is estimated that between 448 and 897 people over the age of 18 years will have a severe learning disability. Data from the NHS Information Centre show that 500 people with a learning disability are receiving a care based service in Gateshead.

The ethnicity of the population identified in the 2001 census was predominantly white British (183,600), with small black and minority ethnic (BME) populations. There is a large orthodox Jewish community within Gateshead. Gateshead is one of the most important seats of Jewish further and higher education in the world.

Gateshead PCT shares the same integrated board and the same chief executive as Sunderland Teaching PCT and South Tyneside PCT who together form the NHS South of Tyne and Wear. The three PCTs have an integrated board that is responsible for strategic planning and development of services across the three PCTs.

Audit Commission CPA Assessment

The Comprehensive Performance Assessment (CPA) scorecard 2007 reported that Gateshead is a council that is improving strongly and demonstrating a 4 star overall performance.

CSCI star rating

Adult social care performance judgements for 2007/08:

- Delivering Outcomes – Excellent
- Capacity to improve – Excellent
- Performance rating - 3 Stars

Gateshead has not had a CSCI Service Inspection within the last year.

The CSCI public website identified 36 care homes for people with learning disabilities in Gateshead's boundaries.

Healthcare Commission annual health check

Gateshead PCT has not had a Standards Based Assessment inspection within the last year.

In the 2007 to 2008 annual health check Gateshead PCT scored 'Good' for both use of resources and quality of services. All of the existing quality of service targets were 'Fully Met'.

Executive summary of findings

Gateshead council and PCT stated a commitment to ensuring that people with learning disabilities and their families were placed at the centre of commissioning arrangements. There were some positive new developments that were inclusive of people with learning disabilities and their carers. However, most people using services said they would like to have greater involvement and influence in the whole system of planning, developing and evaluating services.

The person centred planning process was still at a relatively early stage of development and was not yet adequately driving the commissioning process. Only a few of the people we met with learning disabilities and complex needs had a person centred plan. There were gaps in the skills and availability of communication and advocacy support that needed to be addressed to ensure that people with complex needs were meaningfully involved in planning and commissioning activity. There was work to do to strengthen awareness and build confidence in the complaints process.

There were some outstanding gaps that needed to be addressed to ensure partnership working and the management of resources was fully secured and supported the delivery of improved outcomes. Gateshead council and the PCT did not have a shared and jointly resourced plan for responding to the needs of people with learning disabilities. There was limited information available about the diverse needs of people with a learning disability from black and minority ethnic and faith communities in the area. Work was required to improve the focus on the health and wellbeing needs of people with learning disabilities and to address health inequalities. Few people with a learning disability had a health action plan, although there was evidence of some positive recent developments that should improve awareness and support in this area.

The Supporting People review process and the *In Control* pilot¹ had begun to deliver more flexible and responsive support. However, there were some operational systems and practices to be addressed to support better use and sharing of information and the management of risk between partner organisations, people using services and their families. The specialist learning disability health and social care teams were not integrated or co-located which reduced opportunities for informal sharing of information and feedback between health and social care staff. Tighter management oversight was required in terms of auditing practice and tracking outcomes and risks to people with learning disabilities and complex needs.

There was a particular urgency to comprehensively review the quality of provision for some people placed out of area, including in hospital² settings, and to develop alternative options for those who were no longer required to be detained under the Mental Health Act. Procurement and contract management arrangements needed further development. The council's plans to involve people with a learning disability in quality reviewing services should enable better understanding of the things that mattered most to people with learning disabilities.

¹ Work funded by central government to test new service user led ways of delivering support where people were given a budget to procure and manage their own support

² Independent hospital and NHS provision

The work of the intensive support team was valued and provided accessible support to people with a learning disability in a crisis and out of hours. However, there were a number of areas where joint working needed development to ensure people were consistently enabled to enjoy good health and to have appropriate access to treatment when they needed it.

The council had undertaken a significant change programme to modernise its day services and to promote improved access to further education and employment. There was work required to expand the range of opportunities and support for people with learning disabilities and complex needs so that they had regular access to local social and leisure opportunities.

Some carers were aware of their right to a carer's assessment and valued their recognition and the support provided to them. However, many carers said they lacked information and were not accessing the support they needed. There was a particular gap in the level and availability of support to people living at home with family carers.

Efforts were being made to build the range of providers and to strengthen partnership working so that local services were more flexible in their approach and had greater commitment and capacity to respond to the diverse needs and wishes of individuals. Service commissioners must ensure that contracting processes are centred in the delivery of outcomes and address late notification of fee increase to independent sector providers. The development of individual budgets was welcomed by people with a learning disability and their carers. However, work was required to ensure better support to people managing their own budget and to review staff roles, responsibilities and capacity in supporting the new arrangements.

The council was keen to promote learning and innovation in how services were delivered. However, the Learning Disability Partnership Board was not sufficiently challenging of the improvement and commissioning agenda. Partnership working across health and social care was generally good but needed strengthening in some areas at both strategic and operational levels. The health and social care commissioning organisations had begun to strengthen performance management and quality assurance systems to improve the delivery of outcomes for people using services, but this was from a relatively low base compared with many other areas. Progress in some areas had been limited given issues of staff turnover and gaps in organisational capacity.

Recommendations	
Putting people at the centre of commissioning	<ul style="list-style-type: none"> • The council and PCT should ensure all adults with learning disabilities and complex needs have timely access to person centred support plans that place them at the centre of commissioning. • The council and PCT should ensure people with learning disabilities and complex needs have the communication and advocacy support they require to enable them to be actively involved in and influence how their needs are met. • The council and PCT should ensure feedback from individual assessments of need, support plans and reviews actively informs commissioning priorities. • The council and its partners should provide clear information and support for family carers to enable them to have a better understanding of self directed care and individual budgets. • The council and PCT should review the complaints process in conjunction with people with a learning disability and family carers to ensure increased awareness and confidence in the process.
Understanding the needs of populations and individuals	<ul style="list-style-type: none"> • The council and PCT should develop a shared strategy and action plan for meeting the needs of people with a learning disability and their family carers including agreement about areas for future joint investment. • The council and PCT should address gaps in understanding of the diverse needs of people from black and minority and faith communities living in the area. • The council and PCT should improve the identification of the health needs and address the health inequalities experienced by people with learning disabilities and their carers. • The council and the PCT should address the age related support requirements of people with learning disabilities and their family carers.
Sharing and using information more effectively	<ul style="list-style-type: none"> • The council and PCT should strengthen arrangements for sharing and using information to improve analysis of risk and the management of outcomes. • The council and PCT should ensure tighter management oversight of case recording practices to deliver improved standards and support for people using services.

<p>Assuring high quality providers for all services</p>	<ul style="list-style-type: none"> • The council and PCT should develop shared performance improvement plans for addressing gaps in the level, standard and quality of care provided to people with learning disabilities and complex needs. • The council and PCT should strengthen its arrangements for developing service specifications and contract monitoring and review across the sector. • The council and PCT should ensure greater awareness of individual and organisational roles and responsibilities in managing adult safeguarding activity.
<p>Recognising the importance of good health services; recognising the interdependence between work, health and well-being; recognising human rights</p>	<ul style="list-style-type: none"> • The council and PCT in conjunction with their health partners should identify and address gaps in the provision of health care for people with learning disabilities and complex needs. • The council and PCT should review the quality of provision for people placed out of area and develop alternative options for those individuals who no longer require detention under the Mental Health Act. • The council and PCT should ensure high standards of practice in supporting the human rights of people with learning disabilities and in ensuring greater awareness of and compliance with mental health legislation. • The council in partnership with others should expand the range of social and leisure opportunities for people with learning disabilities and complex needs. • The council and PCT should ensure family carers receive the information and support they require in a timely manner.
<p>Developing incentives for commissioning for health and well-being</p>	<ul style="list-style-type: none"> • The council and PCT should develop their commissioning arrangements to strengthen the focus on commissioning for health and well-being and ensure that service delivery recognises and meets the equality and diversity needs of people with a learning disability. • The council and PCT should develop their arrangements for involving family carers in securing new providers and making changes to existing service provision. • The council should strengthen the range of brokerage and support services available to people using individual budgets and Direct Payments to ensure wider access and confidence in their use.
<p>Making it happen:</p>	<ul style="list-style-type: none"> • The council and PCT in conjunction with provider

local accountability, capability and leadership	organisations should develop shared approaches to workforce planning and development that addressed gaps in existing capacity and expertise. <ul style="list-style-type: none">• The Learning Disability Partnership Board should exercise stronger leadership and challenge of commissioning and service delivery.
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Key review findings

Putting people at the centre of commissioning

Outcome: People with learning disabilities, their families and their carers are routinely involved in the planning, design, development and evaluation of services, resulting in a far more personalised approach to service delivery.

Summary

There was a strong commitment to ensuring that people with learning disabilities and their families were placed at the centre of commissioning arrangements. However, we found a mixed picture as to the extent to which people with learning disabilities and complex needs, their families and their carers were routinely involved in the planning, design, development and evaluation of services. There were some positive new developments that were inclusive of people with learning disabilities and their carers. However, most people using services reported they would like to be more involved in the whole system of planning, developing and evaluating services. Efforts were being made to engage people with learning disabilities and their families in the re-provision of Northumberland, Tyne and Wear NHS residential care services. The market place event held whilst we were on site provided an opportunity for people to have greater awareness of their future options and opportunities to direct how support was provided in the future.

There were gaps in the skills and availability of communication and advocacy support that needed to be addressed to ensure that people with complex needs were meaningfully involved in planning and commissioning activity. The advocacy services acknowledged they had gaps in their knowledge and experience especially when people did not use verbal communication. Case advocacy³ was being used for individuals when the need for advocacy was identified. However, this 'one-off' approach was not sufficiently flexible or responsive in supporting people with complex needs. There was a lack of citizen advocacy despite Your Voice Counts having received a one year grant to employ a citizen advocate co-ordinator⁴ with a brief to recruit volunteers. The speech and language therapy service identified that there were 128 people with a learning disability on their caseload who required communication passports⁵. However, currently only 20 people had these.

Whilst carers and people using the assessment and treatment services had begun to be involved in designing the new service, this was not yet underpinned by a user engagement strategy. Carers from Gateshead needed stronger representation in these developments.

The council and PCT had recognised the need to enhance their service review and monitoring arrangements to enable stronger feedback from people and their families using services. They had plans for strengthening the quality assurance of services to involve people with learning disabilities in undertaking quality audits and so ensure a better understanding of peoples' experiences and the outcomes being

³ The case advocate role is to enable people to speak up and get their views heard on a single case, (they are not long term relationships).

⁴ Citizen advocacy is where ordinary citizens become involved in the life of someone in their community who's vulnerable.

⁵ Communication passport is a tool to support people who are unable to speak for themselves

delivered. Gateshead could benefit from learning from other areas where this approach is now well embedded in their commissioning arrangements.

The person centred planning process was still at a relatively early stage of development and was not yet adequately driving the commissioning process. Only a few of the people we met with learning disabilities and complex needs had a person centred plan. Most of the family carers we met reported that they had experienced frequent changes of care managers and case reviewers. This resulted in them having to repeat their story and led to a perceived lack of continuity of care and uncertainty. There was work to do to ensure feedback from assessments, support plans and review activity actively informed commissioning priorities. Where they existed, there was potential for a stronger focus on the social and leisure needs of the individual to support their full participation and inclusion in the life of their local communities. There was also the need to produce plans that were accessible to the person at the centre of the process.

Efforts were being made to ensure young people and their families in transition to adult services were offered the opportunity to be involved in planning their own support arrangements. The council and PCT had recently enhanced its work force and were tackling waiting lists for assessment and person centred support plans.

People with a learning disability and complex needs and family carers identified that there were some good examples of where they had played a lead role in planning and commissioning services. These included services for people who were receiving individualised budgets including single person supported living services, the Fosdyke respite service and families who were supported by MENCAP through its domiciliary care service. The individuals and family members who were using these services identified that they were flexible and responsive to the changing needs of the individuals and that they were actively involved in the way the services were provided. People who used individual budgets⁶ were generally very happy with how they were involved and the outcomes for them. Comments from people we met included:

"This is the best thing that has happened to me."

"Now if something is not good enough for me, I can change it".

Efforts had been made to strengthen the availability of information to people who used services and their carers. The Accessible Information Resource Service (AIRS) was able to offer information in a range of language and formats. Work was taking place to improve the signposting of carers to services they may require. There needed to be stronger promotion of information and support for family carers to enable them to have a better understanding of self directed care and individual budgets. Some family carers were confused about the process for managing an individual budget saying

"I read about how complicated they [individual budgets] are and I wouldn't be able to manage them".

The number of complaints from people with learning disabilities or their carers was relatively low. Family carers⁷ however identified concerns regarding the time taken for complaints to be resolved. Family carers also voiced concerns that they feared making a complaint could result in a poorer service being provided to their family

⁶ Gateshead was one of the few councils in England to be an individual budget pilot

member and were therefore reluctant to use this route to raise their concerns.

Recommendations

- The council and PCT should ensure all adults with learning disabilities and complex needs have timely access to person centred support plans that place them at the centre of commissioning.
- The council and PCT should ensure people with learning disabilities and complex needs have the communication and advocacy support they require to enable them to be actively involved in and influence how their needs are met.
- The council and PCT should ensure feedback from individual assessments of need, support plans and reviews actively informs commissioning priorities.
- The council and its partners should provide clear information and support for family carers to enable them to have a better understanding of self directed care and individual budgets.
- The council and PCT should review the complaints process in conjunction with people with a learning disability and family carers to ensure increased awareness and confidence in the process.

Understanding the needs of populations and individuals

Outcome: Local authorities and PCTs have an improved understanding of the current and emerging health and social care needs of their learning disability population, particularly those with complex needs, and their family carers, and have secured the resources and investment to meet their requirements.

Summary

The council and PCT had made progress in gathering and sharing information about the needs of people with learning disabilities and their carers to inform future planning and commissioning. However, there were some outstanding gaps that needed to be addressed to ensure partnership working and the management of resources was fully secured and supported the delivery of improved outcomes. Gateshead council and the PCT did not have a shared and jointly resourced plan for responding to the needs of people with learning disabilities. It was not clear how many people there were with a learning disability in Gateshead, what support they required, or what outcomes were being achieved. There was limited information available about the diverse needs of people with a learning disability from black and minority ethnic and faith communities in the area. The PCT and council partnership had produced a Joint Strategic Needs Assessment.⁷ It did not provide a comprehensive picture of the needs of young people in transition, those living with older carers and people with additional mental health or offending related behaviour. This required further development to inform and shape future commissioning of services for people with a learning disability and complex needs. People with a learning disability and family carers had not been involved in the production of the assessment.

The council had strengthened its processes for identifying and supporting young people in transition into adult services. Partnership working between children and

⁷An assessment of the current and future health and wellbeing needs of a population.

adult services staff had been reviewed and improvements had been made to transition planning including the development of multi agency panels to support decision making. However, joint work with young people and their families was still not taking place early enough in some instances. At an operational level there were some concerns about arrangements for assessing young people in transition for entitlement to continuing health care. There was scope to improve partnership working between PCT based commissioners and social care managers to ensure timely funding decisions.

Some good initial work in the area to identify the health needs and inequalities of people with learning disabilities had not been sustained. This was now beginning to be addressed by the council and PCT. However, few people with a learning disability had a health action plan. Positive new developments included the appointment of people with learning disabilities as health trainers. The PCT had strengthened its arrangements for gathering information about the health needs of people with a learning disability from GPs. The PCT had also used Learning Disability Development Fund money to recruit three, six hour posts for people with a learning disability to work with GP surgeries to support the annual health checking process. Further work was required to identify and address the health inequalities experienced by people with learning disabilities and their family carers at a strategic and individual level.

We saw some positive examples of how the partnership was working to modernise services provided to people with a learning disability. This included the development of the new assessment and treatment service, new individualised supported living arrangements, and stronger promotion of the work opportunities service.

There was work required to develop new models of support that addressed the age related needs of people with learning disabilities and their carers. Analysis of the inspection reports for care home providers in the area highlighted growing risks with regard to the appropriateness of existing residential and nursing home support for people with learning disabilities as they aged. There was also work required to get a clearer understanding of the needs of older family carers.

Recommendations

- The council and PCT should develop a shared strategy and action plan for meeting the needs of people with a learning disability and their family carers including agreement about areas for future joint investment.
- The council and PCT should address gaps in understanding of the diverse needs of people with learning disabilities and their family carers from black and minority and faith communities living in the area.
- The council and PCT should improve the identification of the health needs and address the health inequalities experienced by people with learning disabilities and their carers.
- The council and the PCT should address the age related support requirements of people and their family carers.

Sharing and using information more effectively

Outcome: Local authorities and their partners apply the principles of *Putting People First* so that information about people with learning disabilities and complex needs is shared across agencies and used to deliver improved, personalised services and supports, tailored to people's expressed needs and wants.

Summary

The council and its partners were committed to developing services that were responsive to peoples' individual needs and circumstances. The council had benefited from opportunities as a pilot *In Control*⁸ area to explore new ways of delivering and funding services. It had a programme of work to improve access and the costing and sustainability of self directed support and individual budgets. A broker⁹ had been appointed as part of the pilot process but this post had ceased when the funding for the pilot had come to an end. Front line staff were unclear about future arrangements and expressed concerns about their capacity to undertake this role.

There were strong links with Supporting People¹⁰ developments that contribute to the support, planning and re-provision of services for people who were formerly cared for in NHS hospital or local authority run care homes. The review arrangements had been centred in a robust analysis of people's experiences. The process provided an effective challenge to the quality and value for money of services delivered to people with learning disabilities. A significant programme of decommissioning of these services had begun with new services being developed that were more personalised and tailored to peoples' needs and preferences.

However, there were some operational systems and practices to be addressed to support better use and sharing of information and the management of risk between partner organisations, people using services and their families. Protocols for the management, review and sharing of information, inclusive of people placed out of area needed development to provide clear accountability and direction in delivering improved outcomes and effective management of risk. People placed out of area (including some detained under the Mental Health Act) had not been reviewed as frequently as appropriate in some instances and this had led to delays in planning alternatives that supported greater independence.

Health and social care staff identified that sharing and managing confidential information was difficult as all of the partners used different computer systems. This limited the sharing and timely transfer of information between teams and agencies. The specialist learning disability health and social care teams were not integrated or co-located¹¹ which reduced opportunities for informal sharing of information and feedback between health and social care staff. There were no agreed future plans for the development of joint teams.

During the review we experienced problems with accessing personal information

⁸ Work funded by central government to test new service user led ways of delivering support where people were given a budget to procure and manage their own support

⁹ Someone who assists with finding out about support options and the costs of them

¹⁰ Government Grant to deliver housing related support

¹¹ Exception- One social work post aligned to the intensive support team, though this was vacant at the time of our visit

about people using services. There were gaps in electronic and paper based case recording, key information was not available on the Care First system¹² in some cases, information not being adequately completed (outcomes from care plans) and in one case the paper case record had been lost. Tighter management oversight was required in terms of auditing practice and tracking outcomes and risks to people with learning disabilities and complex needs. The council had recognised the gaps and management difficulties experienced by front line staff in inputting and using information to support improved focus on outcomes and had plans for upgrading the system to allow for greater efficiency and flexibility in the management of information.

Recommendations

- The council and PCT should strengthen arrangements for sharing and using information to improve analysis of risk and the management of outcomes.
- The council and PCT should ensure tighter management oversight of case recording practices to deliver improved standards and support for people using services.

Assuring high quality providers for all services

Outcome: People with learning disabilities and complex needs have services and support in places that are personalised according to their needs and reflective/sensitive to changes in their requirements.

Summary

We found that there were some areas where work was required to improve the level, standard and quality of services for people with learning disabilities and complex needs so that their independence and safety were sensitively promoted. There was work to do to shift the practices and enhance the skills of some providers so that they enabled people to lead full and fulfilling lives. CSCI inspection reports of local care homes highlighted some concerns about people with learning disabilities not having their individual needs adequately met when they were placed in larger providers, and the need for some organisations to build their expertise in supporting people with challenging behaviour. There were multiple concerns with regard to the quality of one provider that were taking a long time to address.

There was a particular urgency to comprehensively review the quality of provision for some people placed out of area, including in hospital¹³ settings, and to develop alternative options for those who were no longer required to be detained under the Mental Health Act. This included undertaking a value for money analysis of existing costs and developing a wider range of community services to support timely hospital discharge and recovery.

The council was working to strengthen the procurement and contract management of service providers. The sample of independent sector contract files we examined however highlighted the need to strengthen the focus on standards and outcomes within contract specifications. This included having a stronger focus on safeguarding requirements, equality and diversity issues, and the provision of communication and

¹² case management system used by adult social care

¹³ Independent hospital and NHS provision

advocacy support. There were no service level agreements, service specifications or formal systems for monitoring services directly provided by the council.

Social care commissioners had recently developed a quality framework to support tighter monitoring and review of the performance of providers. This was still at a relatively early stage of development and we were not able to assess its impact as a key driver in improving services. The council had developed new posts to strengthen its contract management and procurement arrangements in recognition of insufficient capacity in this area. The council's plans to develop quality auditing involving people with a learning disability should further promote learning and enhance the focus on the issues that matter most to people with learning disabilities. The carers of one respite service identified close links with the provider organisation and joint working. This approach was valued by carers as a good example of cooperation and joint working.

The council and PCT gave a high priority to ensuring providers complied with the multi agency safeguarding¹⁴ policy and procedures. However, in our interviews with partner agencies and corporate council staff we found variable levels of awareness of the work of the adult safeguarding board and some misunderstanding and uncertainty with regard to safeguarding employment requirements. Some staff highlighted they had not yet had adult safeguarding training and were unclear about responsibilities they and others had in managing the process. There was work required (as is the case nationally) to ensure appropriate safeguarding arrangements underpin the development of individual budgets.

Recommendations

- The council and PCT should develop shared performance improvement plans for addressing gaps in the level, standard and quality of care provided to people with learning disabilities and complex needs.
- The council and PCT should strengthen its arrangements for service specification and contract monitoring and review across the sector.
- The council and PCT should ensure greater awareness of individual and organisational roles and responsibilities in managing adult safeguarding activity.

Recognising the importance of good health services; recognising the interdependence between work, health and well-being; recognising human rights

Outcome: People with learning disabilities and complex needs have the right to live a fulfilling life with good, accessible health care, social care and employment opportunities close to home.

Summary

The partnership was working to deliver improvements in health services for adults with learning disabilities and complex needs. However, there were a number of areas where joint working needed development to ensure people were consistently enabled

¹⁴ Systems for identifying and addressing concerns about the safety and welfare of people whose needs make them vulnerable to ill treatment or exploitation.

to enjoy good health and to have appropriate access to treatment when they needed it.

Health and social care staff expressed concerns about gaps in access to and the support provided by some local health services in meeting the needs of people with learning disabilities. These included their care and treatment whilst using acute hospital care, dental services, GPs and others. There was an over reliance on and high demands placed on family carers when people with learning disabilities were admitted to acute sector hospitals. Some hospital wards did not have access to appropriate equipment to keep people safe in some instances. Family carers were particularly concerned about the lack of understanding and joint working with them by some health professionals in ensuring peoples' needs were holistically identified and addressed. Further work was required to ensure individuals and organisations worked effectively together to make decisions in the best interests of people who lacked capacity to do so for themselves¹⁵. The learning disability liaison nurse previously employed by the PCT was valued by carers. The role had been suspended but recently it had been agreed that the role would be reinstated at the end of March. This should assist with the management of some of these concerns.

Front line health and social care staff were working to support the human rights and the individual choices of people with a learning disability. However, some areas of practice including case records needed development to provide a stronger focus on analysing risks and demonstrating how individual rights and choices were promoted. For one person the reason for detention on a section of the Mental Health Act was not clear. In another case discussion with staff identified that there was some confusion regarding the status of the individual (ie. whether detained under the Act or a voluntary patient) and the risks they posed.

The intensive support team provided accessible support to people with a learning disability in a crisis and out of hours. The introduction of this team had led to fewer in-patient admissions, shorter in-patient admissions and better access to appropriate services on discharge. Many of the people spoken to during the review spoke highly of the support received from the team.

The intensive support team and the mental health team had developed a joint pathway for people with learning disability who required the support of the mental health team. This pathway identified the responsibilities of the different teams to ensure that people with a learning disability and mental health problems received services from staff with the appropriate skills and knowledge both as an in-patient and on discharge. At the time of our review there was reported to be one person whose discharge was delayed given difficulties in securing appropriate local provision.

The council had undertaken a significant change programme to modernise its day services and to promote improved access to further education and employment. The council was working with an increasing range of partners to enhance the opportunities people with learning disabilities had to have a job or volunteer. The local college and work opportunities team provided a range of training and support to people with a learning disability seeking employment. There were 19 people who have completed this training who were on a waiting list for a job.

¹⁵ as required by the Mental Capacity Act

There was work required to expand the range of opportunities and support for people with learning disabilities and complex needs so that they had regular access to local social and leisure opportunities. There was little provision for social and leisure activities in the evening and at the weekend for people living with their families that ran the risk of some people becoming socially isolated.

Very few of the carers who we met during the review had had a carer's needs assessment completed. Some, including those who had been caring for some time were unaware of their right to a carer's assessment and the services available to carers in the area and felt they had been left to *'just get on with it'*. Gateshead Carers Association was able to assist carers in identifying their needs and signposted people to local resources. The carers who used Gateshead Carers Association felt that this was a very helpful resource.

One family carer who had had a carer's needs assessment completed informed the review team

"The assessment has made the world of difference. Without it I would not have been able to continue in full time employment".

However, many carers were not accessing support to help them maintain employment, attend college courses or access leisure activities. Case managers confirmed that there was inadequate family support to enable family carers to have social time during evenings and weekends. There was a particular lack of flexibility in the provision of in home support. One family carer told us:

"We had to cancel our planned outing as x provider could not provide the care we needed on my 40th birthday".

Carers were concerned about the lack of emergency respite provision within the Gateshead area. When emergency provision was required this resulted in the person they cared for having to move out of area.

Recommendations

- The council and PCT in conjunction with their health partners should identify and address gaps in the provision of health care for people with learning disabilities and complex needs.
- The council and PCT should review the quality of provision for people placed out of area and develop alternative options for those individuals who no longer require detention under the Mental Health Act.
- The council and PCT should ensure high standards of practice in supporting the human rights of people with learning disabilities and in ensuring greater awareness of and compliance with mental health legislation.
- The council in partnership with others should expand the range of social and leisure opportunities for people with learning disabilities and complex needs.
- The council and PCT should ensure family carers receive the information and support they require in a timely manner.

Developing incentives for commissioning for health and well-being

Outcome: There is effective partnership working that results in the development of a health and social care market that puts people first, and delivers the kinds of services that are important to them.

Summary

Efforts were being made to build the range of providers and to strengthen partnership working so that local services were more flexible in their approach and had greater commitment and capacity to respond to the diverse needs and wishes of individuals. The partnership was at a relatively early stage in developing incentives for commissioning for health and wellbeing.

The council and PCT were committed to procuring services on the basis of the quality of care being provided. However, there was work required to strengthen approaches to contract specification and monitoring, including analysis of value for money. There was a need for increased rigour in evaluating the performance of providers and in promoting learning about what works. The new quality framework should assist in addressing some of this development agenda. The council also needed to address issues with regard to the late notification of fee increases to independent sector providers.

There was work in progress to extend the range of organisations active in Gateshead to provide greater flexibility and choice. People with learning disabilities and their family carers had been invited to meet over 25 different providers at the recent market place event to develop alternative arrangements for people currently living in Northumberland Tyne and Wear NHS residential care services. Fifteen of these were providers who wished to expand their service into Gateshead. Providers who were not preferred providers or were not willing to employ staff under The Transfer of Undertakings (Protection of Employment) Regulations (TUPE) were also invited to attend. It was not clear what the implications would be for those service users or families showing a preference for one of these providers. Some families reported that they had found this approach helpful and some had been overwhelmed by the choice of providers. The council and PCT needed to learn from this and ensure future events reflected different approaches to build the confidence and involvement of service users.

The PCT had established a sub regional third sector commissioning group, which the council attends, to strengthen the role and contribution of community and voluntary sector organisations. It was working to assist them in building their capacity and competences to assist in the delivery of the *Putting People First* agenda. The Local Involvement Network (LINK) was developing well. Public consultations had helped to identify local organisations to become involved in LINK's. Learning disability groups have been involved in the development meetings and had decided to contribute to the LINK.

Family carers and people with a learning disability and complex needs who were in receipt of individualised budgets reported that that they were personalised and responsive to changes in their circumstances. Support from the Independent Living Fund social worker was valued. However, some people said that they had not received sufficient support with managing the different funding requirements. Some staff reported they were not clear about their responsibilities in monitoring and

reviewing individuals who were in receipt of these payments. There was a need to consider how the broker role could be further developed. These issues identified in the pilot phase needed to be addressed to promote and sustain wider future access to individual budgets. We heard similar concerns with regard to Direct Payments with some carers reporting they had not had sufficient information to make an informed decision and perceived the process to be too time consuming.

There was work to do to ensure commissioning and service delivery recognised and met the equality and diversity needs of individuals including faith, culture, sexuality and sexual orientation. Equality impact assessments were being reviewed by the council, but front line staff had a limited awareness of their impact to date. The Learning Disability Partnership Board had funded Service Access Disability Action (SADA) to report on methods to improve the awareness of the needs of people with a learning disability from a black and minority ethnic group. This report was not yet available to inform service development.

Recommendations

- The council and PCT should develop their commissioning arrangements to strengthen the focus on commissioning for health and well-being and ensure that service delivery recognises and meets the equality and diversity needs of people with a learning disability.
- The council and PCT should develop their arrangements for involving family carers in securing new providers and making changes to existing service provision.
- The council should strengthen the range of support services available to people using individual budgets and Direct Payments to ensure wider access and confidence in their use.

Making it happen: local accountability, capability and leadership

Outcome: People with learning disabilities and complex needs, their families and carers are aware of what services and support they can expect and have a right to receive from councils and the NHS.

Outcome: Commitment at a corporate, strategic and operational level means that local authorities and PCT's know what services need to be delivered and how to deliver them to improve the quality of life for people with learning disabilities and complex needs and their families.

Summary

We found varying levels of awareness by people with learning disabilities and their carers about the services and support they could expect and had a right to receive from the council and PCT. People using services with learning disabilities and their carers needed to receive better information and support to enable them to have a strong voice and to make informed decisions about the things that mattered most to them.

Senior managers across agencies were committed to delivering the best possible opportunities and support to people with learning disabilities and their families. The council and the PCT had a sound knowledge of the policy drivers for improving

services and how these policy drivers informed the development of this agenda.

Partnership working across health and social care was generally good but needed strengthening in some areas at both a strategic and operational level. There were some gaps in the range and quality of provision, areas of weak practice in the management of personal information and joint working by front line staff. There was a particular need to ensure the development of clear joint commissioning strategies and improvement plans underpinned by shared investment priorities. There was specific work force planning, development and training required in some areas to ensure practice consistently achieved the highest possible standards and delivered the best possible outcomes.

The health and social care commissioning organisations had begun to strengthen performance management and quality assurance systems to improve the delivery of outcomes for people using services, but this was from a relatively low base compared with other areas. Progress had been hindered given issues of staff turnover and gaps in organisational capacity. There was an urgent need to address the health inequalities experienced by people with learning disabilities and to ensure that commissioning and service delivery reflected the equality and diversity needs of the whole population.

The council was working to ensure that quality standards were included in the procurement and contractual information for new learning disability services to be developed during 2008 and 2009. The council planned to incorporate the quality standards into all existing contracts and reviewing frameworks by 2011. The council and PCT needed to ensure this performance improvement activity was delivered in a timelier manner. The quality standards framework being rolled out underpinned the *Valuing People Now* agenda. There was a plan to offer training to people with learning disabilities and their family carers as 'quality checkers' for monitoring the quality framework.

The council was keen to promote learning and innovation in how services were delivered. We saw some positive examples of how efforts were being made to deliver support in new and innovative ways. The council had opportunities to learn from its involvement in the pilot for individual budgets. Some of the people in receipt of an individual budget spoke positively about how this had led to improvements in their lives. However, the council and its partners needed to develop robust exit strategies to ensure that initiatives and key posts were not put on hold when external funding ceased.

The Learning Disability Partnership Board was not sufficiently challenging and driving the improvement and commissioning agenda. It needed to review its roles, responsibilities and accountabilities to have a strong and active leadership role in supporting change management and in improving outcomes for local people. The involvement of people with learning disabilities and carers in the work of the Partnership Board needed expansion to ensure that all people with a learning disability were able to effectively contribute either in the meeting through other groups, and actively influenced the priorities and work of the Partnership Board. The Valuing People Now coordinator was seen to provide a good link between the Partnership Board and people with a learning disability.

Recommendations

- The council and PCT in conjunction with provider organisation should develop shared approaches to workforce planning and development that addressed gaps in existing capacity and expertise.
- The Learning Disability Partnership Board should exercise stronger leadership and challenge of commissioning and service delivery.

Joint Learning Disability Commissioning Review

Glossary

Campus Provision	<p>Provides long-term care</p> <ol style="list-style-type: none"> 1. Are through the NHS, in conjunction with NHS ownership/management of housing (residents do not have an independent landlord and housing rights). 2. Is commissioned by the NHS. 3. Includes people who have been in assessment and treatment beds more than 18 months who are not compulsorily detained or undergoing a recognised and validated treatment programme. 4. People living in such accommodation are technically and legally NHS patients.
Care Management	A process where by an individuals needs are assessed and evaluated, eligibility for service is determined, care plans are drafted and implemented and needs are monitored and re-assessed.
Care Manager	A practitioner who, as part of their role undertakes care management.
Care Pathways	A method of organising all of the care a person receives from different professionals and organisations, to make sure it is coordinated.
Care planning	<p>A plan outlining support and care needs for the person. This plan must include the whole person including health needs, emotional well being, employment and leisure.</p> <p>A care plan must be regularly reviewed with the individual and multidisciplinary team if appropriate.</p>
Contingency planning	Plans which are developed for the purpose of 'back up' where the planning factors (e.g. scope, forces, destination, risks, area of responsibility etc.) have been identified or can be assumed. These plans are produced in as much detail as possible, including what is needed and how to do it, as a basis for future planning.
Continuing Care Funding	Fully funded care for people who do not require care in an NHS acute hospital, but who nevertheless require a high degree of ongoing health care. Anybody can qualify for NHS continuing care funding if their needs satisfy eligibility criteria.
Care Programme Approach	A plan of care for people receiving mental health services or support from more than one professional.
Commissioning	<p>Commissioners understand people's needs now and how to plan for the future. They are able to shape services that are fair, of good quality and change in accordance with people's needs and wishes. Commissioners use the resources they have in the most effective ways to ensure that localities have the capacity to meet people's needs and wishes.</p> <p>Commissioning includes a range of activities, such as:</p>

	<ul style="list-style-type: none"> ▪ Knowing what services people need to live a good life ▪ Using this knowledge to plan changes for the whole local area ▪ Taking action to change services where they are not good enough ▪ Paying for services to meet individual needs ▪ Checking that outcomes from services are of a good quality and changing services and plans if needed
Directed Enhanced Services	Directed Enhanced Services are special services or activities provided by GP practices that have been negotiated nationally. During 2008 learning disabilities were included and are funded to run until 31 March 2010. GP practices are funded to provide annual health checks for people on the local authority learning disability register. To participate in this DES, practices need to attend a multi professional education session run by their PCT. Practices will get £100 for every health check).
Direct Payments	Local council payments for people who have been assessed as eligible for help from social services and who would like to arrange and pay for their own care and support services instead of getting them from the council.
Forensic Services	Services offered to people who are likely to become a danger to themselves or others and as a result have been or likely to be in contact with the law
Gap analysis	The difference between what is needed and what is available. The difference between where you are and where you want to be.
Health Action Plans	A Health Action Plan (HAP) details the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the individual and the range of services and supports they need, if they are to have better health. Health Action Plans need to be supported by wider changes that assist and sustain this individual approach. The Plan is primarily for the person with learning disabilities and is usually co-produced with them.
Health facilitator	<p>Someone to help support and navigate people through the NHS to access the best and most appropriate healthcare.</p> <p>Health Facilitation involves both casework to help people access mainstream services and also development work within mainstream services to help all parts of the NHS to develop the necessary skills.</p>
Independent Advocacy services	Services which support a person with learning disabilities either as an individual or as a group to raise issues with councils or Primary Care Trusts when making decisions about situations which directly affect their life.
Independent provider	Any private, voluntary, or not for profit provider that physically delivers health or social care services.
Joint Strategic Needs Assessment	A process that identifies current and future health and wellbeing needs in light of existing services, and informs future service planning taking into account evidence of effectiveness. Joint Strategic Needs Assessment identifies 'the big picture' in terms of the health and wellbeing needs and inequalities of a local population.

Learning Disability Development Fund	Money from the government to pay for some of the new ways of working in the Valuing People strategy. Learning Disability Partnership Boards influence locally the way in which this money is spent.
Learning Disability Partnership Board	The Board brings together council departments, health services and other sectors that give people with learning disabilities support. This means that everyone can share information about what is happening in the local area. Partnership Boards are to take responsibility for local delivery of the Valuing People strategy, led by the local Council and with the active participation of all key stakeholders.
Local Area Agreement	Three-year funding arrangement between central Government and a local area, as represented by a Local Strategic Partnership (LSP) The LSP will set out a plan of priorities for its area, in return for greater flexibility of funding streams.
Out of Area Placement	Adult social services and or Primary Care Trusts commission placements of individuals from the council area in provision outside of the council geographical area.
Patient Advice Liaison Service	A service to help patients, their families and carers, to find answers to questions or concerns regarding the care or treatment they receive from all NHS services.
People with Learning disability and complex needs	<p>For this review the definition of people with learning disabilities and complex needs are : 16 years old and over, and experience difficulties because of:</p> <ul style="list-style-type: none"> • The extent of their intellectual impairment, • Having physical disabilities which severely affect their ability to be independent • Having sensory disabilities, which severely affect their ability to be independent • Having a combination of physical and/or sensory disabilities • Any behaviour that can severely challenge services • Having a form of autistic spectrum disorder • Having complex health needs • Having enduring mental health needs • Having a forensic history. <p>And their needs require health or social care organisations to provide ongoing support and assistance, no matter how this is funded.</p>
Person centred approaches	<p>Person centred approaches look at the whole of the person and the whole of their lives, support networks, family, friends, health, leisure, education and employment needs.</p> <p>Person centred approaches are based on the ownership of the planning process by the individual with learning disabilities.</p>
Person centred planning	Person Centred Planning means putting the person at the centre of planning for their lives and at the centre of the services they receive.

	<p>Person centred planning is about:</p> <ul style="list-style-type: none"> • Listening to and learning about what people want from their lives • Helping people to think about what they want now and in the future • Family, friends, professionals and services working together with the person to make this happen.
Safeguarding people arrangements	The systems, processes and practices in place to safeguard people from abuse. Councils lead and coordinate local arrangements with partner organisations.
Self directed support	People who are eligible for social care knowing what they are entitled to and controlling the way they use their money to get the support they need in they way they want it.
Strategic planning	Strategic planning is an organisation's process of defining its strategy, or direction, and making decisions on allocating its resources to pursue this strategy, including its capital and people.
Supervision	A structure by which management oversees the performance or operation of a person or group.
Transition	When someone moves from one time in their life into another. For instance, when children are moving into adulthood, adults move in to older adult services. It can also mean when people have major changes in their life, for instance when some one moves home.

Appendix

Review background and methodology

This joint review has been commissioned by the three commissions due in part to the findings of the national audit for specialist inpatient services 2007 by the Healthcare Commission and the Healthcare Commission and Commission for Social Care Inspection (CSCI) joint investigation into Cornwall Partnership Trust and Sutton and Merton. It also sits in the context of high level reports that have recently been published highlighting poor health and social care services and commissioning practice: *Death by Indifference*, Mencap, Mansell 2 and the Disability Rights Commission *Equal treatment, closing the gap*, and most recently the Joint Committee on Human Rights *A Life Like Any Other?* and the *Sir Jonathan Michael Inquiry*.

There is also a revised edition of *Valuing People* due to be published later this year which has had considerable consultation and is expected to address specifically issues facing people who have more complex needs.

The methodology for the joint reviews was devised with an expert reference group which included people with learning disabilities, family carers, commissioners in local authorities and the NHS, academics, *Valuing People* Support Team and the Department of Health.

An assessment framework was used to assess how well the local council and PCT were commissioning services and support for people with learning disabilities and complex needs. The assessment framework has eight high level statements with a set of outcomes and underpinning descriptors. The review team based the assessment framework on the *Commissioning Framework for Health and Wellbeing* (Department of Health 2007).

The joint review process was designed to reduce demands on the council and PCT. Before visiting Gateshead the review team collated and analysed nationally available data held by CSCI, Mental Health Act Commission (MHAC), Healthcare Commission, the Office of National Statistics, key information graphical system and the information centre. The team also gathered information from the council and PCT in the form of a self-assessment document, which provided evidence unavailable from elsewhere. The strategic health authority, *Valuing People* Support Team and the Audit Commission were also asked about the commissioning practice within the area.

The purpose of the site visit was to:

- Further explore findings from the data analysis
- Focus on the experiences and outcomes for people with learning disabilities and complex needs and their family carers

During the site visit the review team met with people who use services, their families and carers, staff and managers from the council and PCT and representatives of other organisations. The following activities were included as part of the review visit:

- “A day in the life of...” which involved spending time with people with learning disabilities and complex needs
- Mystery shopping
- Interviews

- Meetings
- Focus groups
- Good practice visits
- An Open to the public session