

DH Review: Winterbourne View Hospital

Good Practice Case Studies



WINTERBOURNE VIEW: INTERIM REPORT

GOOD PRACTICE CASE STUDIES

Introduction

As part of the DH Review we have collated three in-depth case studies which highlight examples of good practice where there is minimal use of inpatient services for assessment and treatment (A&T) and setting out in some detail how good services can be provided locally. These examples are from:

- Tower Hamlets,
- Salford and
- Cambridgeshire.

The case studies cover essential points around the range of services provided for people with learning disabilities or autism and behaviour described as challenging and the ways in which these areas have moved away from using A&T units and developed local services.

Below is a brief outline of the key features of each case study:

Tower Hamlets

- Genuine person centred, culturally appropriate health and social care helping to prevent the development of mental health problems
- A reactive service with a pooled budget that actively uses social care alternatives to hospital admission in a crisis
- Very close and intensive working with adult mental health services to allow use of crisis services and brief, focussed inpatient admissions in the generic mental health service

Salford

- Joint commissioning and use of pooled budget
- Strong links between health and local authority
- Clear joint working across multi-professionals
- Process to support people to return to Salford
- Partnership working with commissioned services
- Training for providers

TOWER HAMLETS CASE STUDY

What services do you provide now?

1. Describe your local area

Tower Hamlets is an inner London Borough. It has an estimated population in 2012 of about 252,440. It is estimated that there are about 6,000 people with a learning disability in the borough, with about 1,000 known to the community learning disability service, and about 750 people in receipt of services for people with learning disability. The population is relatively young, and about a third of adults and over half of the population under 18 are of Bangladeshi ethnicity. The population and learning disability factsheets from the Joint Strategic Needs Assessment give further details and are available [here](http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx): (http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx).

2. How are services commissioned?

There is a pooled budget arrangement under section 75 of the NHS Act. Joint Commissioning arrangements are in place which are led by the local authority.

The commissioning service support services that promote independence. Most people are supported to live independently and Tower Hamlets spends the second lowest proportion of gross social care expenditure on residential and nursing care for adults with a learning disability. However, due to complex and high needs it is necessary to commission residential and nursing care. In doing so we choose providers who offer safe and respectful practice that involves service users and their carers.

A brokerage service is used to identify providers that can meet an individual's needs and undertake financial negotiations.

- How do you identify people most at risk in your planning, JSNAs etc

Based on the index of multiple deprivation Tower Hamlets is the third most deprived area in the country. Prevalence of learning disabilities in Tower Hamlets is generally high and tends to be higher in the Bangladeshi, south Asian and migrant communities in general which is believed to be due to poorer antenatal and neo natal care and poor access to health care.

The Joint Strategic Needs Assessment process in Tower Hamlets is robust and inclusive including representation from the community, statutory sector and service user and carer representation. There has been wide consultation on the outcomes in the JSNA and supports generally the principles of the recent Marmot /Review Fair Society 2010, which looks at the principles of improving

health and wellbeing by reducing inequality and poor access to health care. As a result the Community Learning Disability Service is working closely with GPs and primary care professionals to ensure that annual health checks happen for people with learning disabilities thereby improving their chances of identifying common health problems such as diabetes and heart conditions.

3. Interdisciplinary community teams

We operate four integrated interdisciplinary teams within the community learning disability service, based on predominant client need. The four teams are

- Mental Health and Challenging Needs
- Community Health and Wellbeing
- Complex Physical Health
- Transition

Each team contains a range of health professionals and social workers. Each service user is allocated to a particular team, but staff within the learning disability service can work flexibly across the teams if this is the best way to meet the person's needs. Professionals within our team work together in a coordinated way to organise personalised social care, provide specialist healthcare interventions, and support people to access mainstream services.

For people with mental health problems and with challenging behaviour, we will provide direct psychology, psychiatry, nursing, occupational therapy and speech and language therapy interventions as appropriate to people's needs, and in an integrated manner. There will always be a lead professional, often the social worker, who will organise a flexible and person centred care package.

4. What other local services are you involved with?

- What use do you make of local MH services

We make extensive use of local mental health services, and play a very active role in supporting people with learning disability to do so. This is backed up by an agreed protocol with adult mental health services, and having the psychiatrists in the Community Learning Disability Service employed by the local mental health trust to enable local and strategic links. The services we mostly use are

- **Adult mental health inpatient services:** for anyone with a mild or sometimes moderate learning disability who present with an acute mental illness requiring inpatient admission, this would be the first port of call. We support such admissions by providing detailed written clinical information including clinical and risk assessments, by close face to face liaison with the inpatient staff, especially the doctors, psychologists and nurses, by ensuring that someone from the learning disability team attends every ward

round/decision making meeting, and by ensuring that discharges are not delayed, particularly by ensuring that social care required for discharge is provided in a timely manner.

- **Home Treatment Team:** this provides emergency treatment at home for people in mental health crisis, and supports discharge from hospital. We have established excellent relations with this team, and rather than handing over cases to them (as Community Mental Health Teams do) we co-work with them, doing joint visits within working hours, to support them to provide an out of hours service to our clients.
- **Psychiatric Liaison Service** at the Royal London Hospital – this service is where psychiatric assessments are carried outside of working hours. If we suspect our service users will present we send information, and have ensured that our information systems are also accessible to them. They inform us whenever our services users present, and we liaise to develop appropriate follow up. All the psychiatrists in the learning disability service contribute to the rota providing this service.

5. What support do you provide in a crisis?

The Home Treatment Team described above is a crisis intervention service. We try to support people in mental health crisis in the community: at home in addition to the Home Treatment team we might provide extra support workers, and increased monitoring and review from clinical staff, especially nursing and psychiatry. Psychology can sometimes work with the client and their family to resolve the emotional and behavioural difficulties associated with the mental health crisis.

We can also provide other community options, particularly respite care, using the local respite services, but also other providers. We also provide emergency social care placements, e.g. in supported housing.

6. Use of assessment & treatment beds

There is no local assessment treatment service in the borough, the nearest is in Redbridge at Goodmayes Hospital. In the last 3 years two people have used this service, both for just over a week. We have not used other assessment and treatment services in the past 3 years.

We do have 4 people in secure (forensic) inpatient services. These are all in the local service provided by East London NHS Foundation Trust. We work closely with this service to ensure people are discharge promptly and appropriately.

7. How do you involve people and their family carers?

People and their carers are centrally involved in clinical decision making. We have also consulted service users and carers about out of area inpatient admissions. This led to the development of a local secure (forensic) service for people with learning disability, and all people needing forensic services are now receiving these locally, which is in line with the majority of users and carers views.

We also offer family interventions such as meetings to discuss their family member, and also more formal systemic therapy.

8. How have you changed your model of care? What are the key things to do in moving away from A&T units?

Several factors contribute to this. Flexible social care provision is essential, so truly personalised care plans that really address people's needs are crucial. Integrated community teams and pooled budgets are also crucial, so admission is not seen as saving social care money. The community team does lots of work to facilitate access to mainstream mental health, without which people with learning disability are likely to be rejected from such services, or receive significantly suboptimal treatment.

In Tower Hamlets, many of the patients are from families of Bangladeshi heritage. Cultural understanding is essential. Many families are keen to keep people in the family home, provided they have culturally appropriate support, so we work hard to provide this.

Much of the work of the service is aimed at preventing mental health problems and challenging behaviour. Person centred planning that genuinely incorporates choice, promoting independence, regular exercise, constructive activity, and healthy lifestyles all help address this. We also offer counselling and therapy to people with learning disability and their carers and families that can help to address problems early on.

In terms of outcomes, we have very low use of assessment and treatment beds, and the admissions we have are very short. We do not have long admissions to adult mental health, as we work to get people out as quickly as possible. We are able to provide a reactive service, so relapse of mental health problems is picked up early and hopefully prevent costs that would be incurred if treatment were delayed and the relapse more severe.

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SALFORD CASE STUDY

What services do you provide now?

1. Describe your local area

The city of Salford covers 37 square miles and the eight districts of Salford; the population is approx 220,000. Salford is an Inner City Urban environment with a developing economy based on organisations such as the BBC coming here. In terms of numbers of people with learning disabilities within Salford, there are about 350 children and 800 adults who are on the dedicated registers. National data suggests that about 0.6% of the population have a severe/profound learning disability and about 2.5% have a mild/moderate learning disability

2. How are services commissioned?

The model of support operated in Salford looks to change the environment in which people live and reduce their frustration and challenging behaviour. We have been long-term supporters of Mansell. We have two priorities: that people remain living in Salford and that any Salford resident is supported to return to Salford. This requires capacity building Local Services and skilling up staff throughout the service with a strong Clinical lead from Psychiatry and Psychology.

Since 2002 Salford has successfully managed a Pooled Budget between Salford City Council and Salford NHS via section 75 of Health Act. This has helped the setting up of a seamless one point of entry service where support is not divided into Health and Social Care. At the same time a model of joint commissioning was introduced in line with Valuing people 2001. Like Mansell the Values inherent in Valuing People are central to the support we offer. This requires a strong commitment to advocacy, person centred support and planning with people.

A jointly managed integrated team was developed to implement shared risk taking but also manage the pooled budget. The pooled budget has a single responsible commissioner for learning disability who is managed by the assistant director for all joint commissioning in Salford.

Over the years strong Partnership arrangements have been developed with Health and City Council Departments to see people access the mainstream.

To assist with keeping people in Salford, Adult Social Care has Neighbourhoods, Culture, Leisure and Health Improvement in the same Directorate. This focuses staff on building choice and opportunities for people.

To assist with bringing people home Salford has developed a coming home plan, which guides staff through the process of returning people to Salford. In the

development of this Salford has a series of essential / catalytic / collaborative meetings that support the service to implement the coming home plan. The coming home plan looks to develop and implement the messages within Mansell report, and assist with the development of a diverse set of providers of which the service looks to help support to develop capability and capacity to support the most complex people.

A single service approach with clearly identified objectives allows the service to be flexible in returning people back to Salford and maintaining placements. Strong links have also been built with adult safeguarding to ensure that safeguarding policies are implemented and are used as a proactive way to highlight issues but also identify working solutions, encouraging all providers to be transparent in the support provided.

Any commissioned service is based on the principle of ordinary homes in ordinary streets; therefore we try to apply the standard of an ordinary life where people are included as Citizens. There is no residential care in Salford specific to people with Learning Difficulties. The whole service has a clear understanding of who the priority people are and this is constantly reviewed via the input they require from all parts of the service

Clear lines of communication have been established between management and case managers including Allied health professionals.

There are a number of mechanisms that support future planning and service development, this includes Out of Area, Challenging behaviour Strategy group, Partnership board, staying health task group, transition task group, and Provider forum where Commissioners and Providers act collaboratively

Specialised commissioning liaison meetings. Specific Learning disability CQUINS developed annually with local NHS foundation trust and mental health trust

3. Interdisciplinary community teams

The whole Learning disability service is managed by a single assistant director from Salford city council

Community Team

- 1 Principal manager
- 2 Team managers
- 1 Health facilitator
- 1 Senior Practitioner
- 8 Learning Disability Nurses
- 5 Social workers
- 1 Carers Social worker
- 5 Community Assessment officers
- 1 Transition worker

The community team are divided into the eight districts of Salford, people supported are then allocated to appropriate workers within the patch. This helps links with Community Services. All members of the community team are allocated referrals via a central contact centre, and people are supported according to need and priority. Each house where people live has a Coordinator from the team rather than each person having a different worker. The community team operate a duty system which also incorporates PACE duty and DOLS referrals. Each patch is allocated a number of out of area individuals to ensure all reviews are actioned and regular contact is maintained. Members of the community team also chair safeguarding meetings and manage with support the Salford safeguarding process.

If individuals require specialist assessment or interventions by LDHP then an internal referral system exists. LDHP team consists of

- 1 Consultant Psychologist 1 WTE (1 Clinical psychologist, 1 Clinical Nurse Specialist, 1 Psychology Assistant all 1WTE, 0.2 WTE volunteer Psychology Assistant, 0.6WTE trainee Clinical Psychologist)
- 1 AHP manager 0.4WTE (SALT 1 WTE, Physio 2WTE, OT 1 WTE, 1.6WTE Art therapy 1 Total communicator co-ordinator 1 WTE)
- 1 consultant Clinical Psychiatrist (1 SPR 1 SHO)

The LDHP team hold weekly referral meetings to allocate individuals to the most appropriate professional pathway, this assists with identifying and allocating priority people and may include people who are out of area.

The clinical psychology team with the LD service take the clinical lead in the process of bringing people back to Salford and prevention of placement breakdown, and the community team take the commissioning lead.

Another main work stream for psychology team is the development of capacity and capability of the wider workforce of commissioned services in Salford and families. The psychology team hold regular meetings with managers from community team to ensure appropriate allocation and priority to referrals

Services commissioned in Salford

- Day Services x 3 (Staff employed by SCC) within day service a Development Team which consists of (2 WTE Person centred planning workers, 1 WTE development workers for learning disability services, 1 WTE Autism development worker
- Short-term Breaks (1 Respite centre) (Staff employed by SCC)
- Shared Lives Adult placement (Staff employed by SCC)
- Supported tenancy service 16 property's (Staff employed by SCC)
- Supported Tenancy service independent providers +40 property's

- Supported employment
- Garden centre (Social enterprise)
- Individualised community support as required for individuals

4. What other local services are you involved with?

As already outlined there is a strong commitment to opening up ordinary opportunities and multi agency working. There are also partnerships within the arena of Health and Social Care with an emphasis on joint working with Mental Health.

- There is a Full time dedicated Learning Disability psychiatry team, which links in with Learning Disability management systems
- Joint working protocols with MH, LD service and older adults
- Joint care co-ordination between LD and MH for identified individuals
- Training of generic mental health services i.e. IAPT
- Use of community mental health teams for routine support for individuals in the community who have LD and MH
- Use of beds at local generic mental health trust
- Links with older adult service for dementia services,
- Links with other services across the northwest to ensure sharing of best practice

5. What support do you provide in a crisis?

As the service seeks to plan support there are very few crises and people continue to live in the same place. In eight years there has been 5 breakdowns of placement with three people returning to Salford to live within two years of the crisis happening. There are no dedicated special teams or Residential care beds as we have built up capacity in the overall service to support people through their frustrations in their living situation.

In response to a crisis, there are clear policy and procedure guidelines which seek a measured and supportive reaction to challenges. The Challenging Behaviour Policy highlights the use of the Challenging behaviour service leads as first point of advice and support.

Early intervention support is also provided by the Challenging behaviour pathway in terms of Challenging behaviour consultation sessions, training. Detailed communication between psychiatry, psychology team and community teams. The success of this can be seen from the fact that only 6 people have a written up programme for physical intervention. This figure has diminished over the last 5 years.

Physical health checks or interventions including admissions are seen as a clear priority and this may involve the use of our links with the local hospital via their assistant director for safeguarding who will liaise with appropriate hospital

departments to ensure a joined up approach or development of individualised hospital admission pathways.

Salford does not have a specific crisis team, but utilises mechanisms highlighted above to assist with early identification to situations and prompt input at this early stage.

The workforce of commissioned services has free access to training around challenging behaviour including crisis management, this training is clearly monitored and staff are required to regularly attend updates. The training concentrates on very clear proactive positive behaviour strategies as well as covering least restrictive reactive strategies. Where required additional hours are commissioned for people, and this maybe to facilitate environmental changes for the person in crisis which may include consideration of service changes required for the person to continue to live in their home.

As part of a Multi Agency approach there has been research into staff burnout and expressed emotion when dealing with CB and also research into friendships. There has been Involvement with Liverpool LD services and Liverpool University in Human rights risk assessments and least restrictive support strategies. Use of annual restrictive practice audit across all services commissioned in Salford.

Data is collected about individuals and services in relation to frequency, severity of incidents of Challenging behaviour. There is ongoing development of Salford wide challenging behaviour policy which all providers sign up to. The policy is used to ensure that least restrictive practices are used rather than to improve the way staff restrain people. An easy read version of this policy has been developed by people supported in Salford.

6. Use of assessment & treatment beds:

Over the last three years we have only had one requirement of assessment and treatment unit and this initially used local mental health service before transfer to specific unit that had been individually identified as being able to provide short term rehab until they were able to return to Salford.

In the last three years the only other admission to secure setting has been a transfer from a HMP to secure hospital and this was facilitated via Northwest Specialised Commissioning

7. How do you involve people and their family carers.

As already stated there is a strong commitment to work in Partnership with people and their carers. Person Centred Support and the advent of personalisation requires greater choice and control for people .The Partnership Board and sub groups work to see that planning, managing change and monitoring of progress is done together.

All training that is offered to staff is also offered to parents and carers, this helps with joint working with families as they have had the same information that staff receive to add to their expert knowledge of their family member. Within the assessment process of either returning or maintaining placements family involvement with the assessment process. Parents have also been involved in training of new staff who are to support their relatives. Parents and people supported have also played an active role in recruitment of new staff to the psychology team.

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CAMBRIDGESHIRE CASE STUDY

Local area and history of service development in LD

Cambridgeshire is a predominately rural county with a population of approximately 600,000. Peterborough, previously part of the county, is now a unitary authority and has its own commissioning and providing arrangements for people with learning disabilities (LD). Based on the recommendations from the Department of Health Report published in 1993 by a group chaired by the late Professor Mansell (Services for adults with challenging behaviour and/or mental health needs) specialist community multidisciplinary teams for adults with LD were first developed in the south of Cambridgeshire in the mid 1990's. Ida Darwin Hospital was closed as a place of social care and funding was released for team development. At that time services in Fenland and Peterborough were provided by a different Trust and Huntingdonshire already had a community team. The strategy, jointly agreed by health and the Local Authority (LA), in accordance with Government policy (NHS and Community Care Act 1991) was to support the development of a market for social care providers from which social and day care services could be commissioned by the Local Authority (LA). In parallel community-based interdisciplinary specialist health teams for adults with LD were developed to provide additional health expertise to people with LD and those providing support. The community teams were therefore established to ensure that particular skills were available to meet specific health needs such as in the case of people with challenging behaviour and/or mental health needs ensuring that accepted models for understanding, preventing and managing challenging behaviour could be applied. It was argued that social care providers could not be expected by themselves to have the range of expertise necessary and, where assessments were required because of concerns over challenging behaviour, these assessments would be undertaken by health disciplines in the teams in partnership with people with LD, families and other support providers under the aegis of the NHS.

Recent history

Since 2001, following the Health Act, the Local Authority, in the form of the Cambridgeshire Learning Disability Partnership (LDP), has been the lead authority for adult LD services across the county. Approximately 2400 adults with LD are known to the LDP although this represents only a proportion of adults with LD who live in the county. It is not policy to specifically identify and list people with challenging behaviour as any person with LD could potentially develop such problems and those that are presenting with challenging behaviour at one point may not continue to do so once the reasons for such behaviour are identified and informed interventions are undertaken. However, as described below, it is a core responsibility of those working in the community teams to work closely with those organisations commissioned to provide social support so as to develop strategies

that minimise the risk of such behaviour and provide informed and theoretical sound interventions when someone is presenting with such difficulties. It was proposed that the model developed in the south of the county following the closure of Ida Darwin Hospital in the 1990's would be expanded across the county, however, this has not happened and recent investigations undertaken of the county-wide specialist LD services by the NIHR CLAHRC for Peterborough and Cambridge have highlighted very specific structural and organisational difficulties that have impeded the subsequent development of the service (see below).

Commissioning arrangements

Cambridgeshire has joint commissioning arrangements with a pooled budget. In principle, the organisation and planning of the service is undertaken through shared protocols between the LA and the PCT and based on joint strategic needs assessments. Cambridgeshire has recently been selected as having pathfinder status for LD as part of the GP commissioning arrangements. At the regional level a Health and Wellbeing Board for LD has been established chaired by a representative from one of the LAs.

District-based services for people with LD

Services for adults with LD in Cambridgeshire are configured in the following way. Social support (including day/employment opportunities) is commissioned by the LDP and provided by a number of third sector or private social care organisations across the county. All people with LD are registered with a general practitioner, who is responsible for general health matters and for annual health checks. Everyone has access to generic secondary health care services with support to access such care being provided by families or by whichever third sector or independent organisation commissioned to provide social support. The level of that paid support, however, is very dependent on whether or not the given individual meets the necessary eligibility criteria and how individuals spend their personal budgets. There are five integrated (i.e. joint with health and the LA) interdisciplinary community teams for adults with LD across the county – City, East, Fenland, Huntingdon, and South. These teams serve local populations of between 80,000 to 180,000. Because of historic variations across the county in service developments there are differences in team resources but in principle each team have the following disciplines either in the teams or available to them as and when necessary: art and music therapy, care management, clinical psychology, occupational therapy, physiotherapy, specialist LD psychiatry, specialist LD nursing, and speech and language therapy. Some teams have chosen to have behavioural nurse specialists. The teams are directly managed by the LDP with care managers employed by the LA and health professionals employed by Cambridge and Peterborough Foundation NHS Trust (CPFT). Each team has a team manager who is answerable to an area manager.

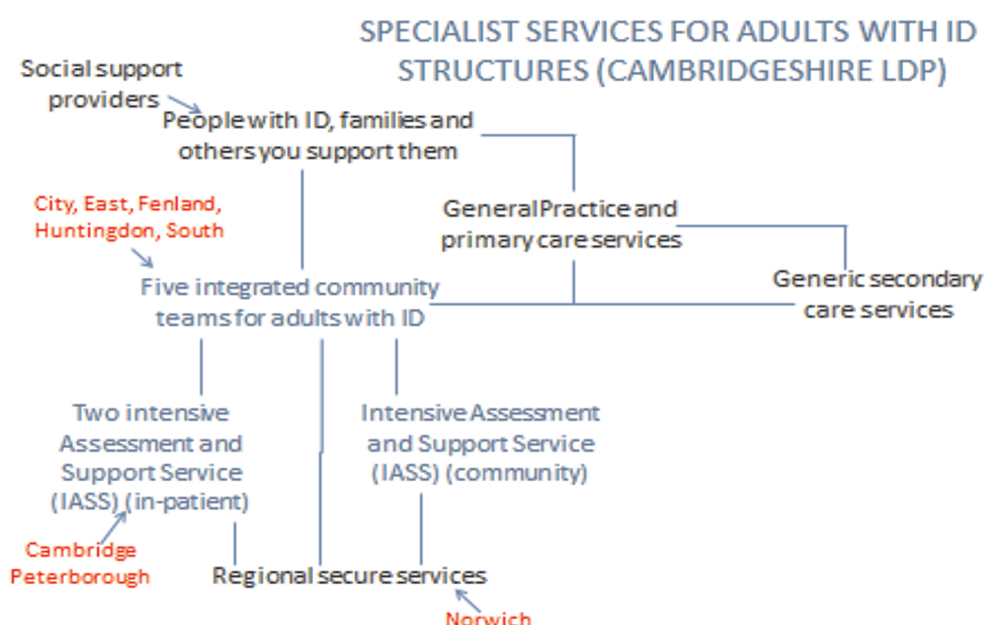
When services were developed in the south of the county the case was made for district-based community teams with the above disciplines on the basis of need. The general nature and extent of need being determined through published research and on the understanding that there were certain needs that could not readily be met through existing generic services. In summary these include the following: discharging the LA's responsibility for care management under the NHS and Community Care Act; more general tasks such as working with social care providers to establish appropriate communication strategies in people's homes (visual timetables, use of makaton, etc), guidance about specific health matters perhaps relating to someone with a specific syndrome, support for further skills development, guidance and support when accessing secondary care services, and matters relating to adult life such as relationships and sexuality. In addition it was proposed that the teams should be directly responsible for assessment and treatment in four specific areas of health where multi-disciplinary involvement is often essential and where generic service are not readily able to provide such services: a) mental ill-health and challenging behaviour (the commonest cause of carer stress and placement breakdown); b) the need for assistance with eating and drinking in cases of dysphagia or for other reasons (to reduce the risk of associated morbidity and mortality); c) epilepsy (in collaboration with neurologists) particular where such epilepsy is complex or associated with behaviour problems or mental state abnormalities (to reduce the risk of sudden epilepsy related deaths and to improve wellbeing); and d) interfacing with the criminal justice agencies if a person with LD was suspected, charged or convicted of an offence (to ensure access to justice and the necessary interventions in partnership with criminal justice agencies). In these four areas the teams would be seen as having lead responsibility but in discharging these responsibilities may also link with other services if required.

What other specialist LD services are available?

These interdisciplinary community teams are therefore the point of access on these matters and receive referrals directly from people with LD and/or their families or paid support workers, or from the GP. Together with primary care, it was also proposed that the community teams would support access to other generic services as and when it was appropriate - including access to mainstream mental health services if those services were the best to meet that person's needs at that point in time. It would clearly be discriminatory if that was not the case but often needs relating to behaviour are not readily met by generic services and just as in other areas of health more specialist support is required (as described below). In addition, community teams have direct access to two other local specialist LD services: a) two small in-patient NHS hospital-based services for people with LD who genuinely require temporary admission to hospital because of mental-ill health or for assessment because of being charged or convicted of an offence – one service is in Cambridge and one in Peterborough. In total 10 beds are commissioned by the LDP for the county. Although commissioned by the LDP these beds are directly managed by

Cambridge and Peterborough Foundation NHS Trust; and b) originally funded for the south of the county only there is a tertiary team referred to as the Intensive Assessment and Support Service (IASS) community team. This is a small team with nursing, psychiatry, and psychology time that community teams can refer to when intensive work is required for someone in the community and teams do not have the resources that can readily be released to undertake such work. In practice the majority of people this team works with are those with severe challenging behaviour some of whom have been convicted of a serious offence – this team is similar to a crisis intervention team but in general receives its referrals through community teams (the only exception is where people are out-of-area then the IASS community team may be directly involved to bring them back into county). Absolutely essential to this model is the concept that the in-patient services and the IASS community team are resources for the district-based community teams to access. It is these community teams that have long term responsibility for working with individuals with LD and the organisation supporting them and if either of the other services becomes involved it is at the request of the teams and it is only on a temporary basis to undertake a specific task. A final resource is access to secure hospital provision. This is not provided as a local level but in principle is available in NHS provision regionally (in Norwich and Hertfordshire) or through the private sector. Such provision should again be seen as a resource available to community teams and used only when secure hospital-based provision is genuinely needed and where assessment in such a setting, usually under the MHA, is justified. This relationship has been problematic but it is crucial that admission to such services is via the local teams who have long term responsibility and that the purpose of the admission is clarified at the beginning and the local team remains involved. If the above services and such a relationship as described above had existed in the case of Winterbourne View people may not need to have been admitted in the first place and, if they had, concerns about management might have been identified through reviews.

Figure: Schematic representation of specialist LD services in Cambridgeshire



Provision of support in a crisis

Where a community team is working well it will have a strong presence in the geographic area it serves. There should be close links with people with LD and their families and also with social care providers, GPs and other agencies. It is these relationships and the quality of social support and the willingness of social care providers to work in partnership that reduces the risk of crises. Ideally all social care provision for people with LD should have appropriate communication strategies designed to help reduce anxiety and to aid understanding around complex concepts such as planning, time etc – particularly important for people with LD and additional autism spectrum disorders. Care plans should be developed based on a sound understanding of the person and his/her needs – people with LD are a highly heterogeneous group with often very specific and sometimes multiple health needs. Whilst social support is provided in the context of a social model, it is the application of other relevant models to an understanding of a person's needs with respect to their health, behaviour and general functioning that can be critical in ensuring the success of care and preventing crises and placement breakdown. It is the community teams that have this responsibility to respond to crises and they in turn have access to the other services mentioned above. Whilst there used to be an after-hours on call psychiatrist in LD this is no longer the case. Primary care and mental health services are available after hours.

Assessment and treatment

LD services were conceived on the basis that assessment and treatment takes place wherever and in whatever setting it is required, most importantly in the community, at people's homes etc. It is not necessary, and may even be counter-productive, for assessment and treatment to be confined to 'an assessment and treatment unit'. The latter is only required under very specific situations usually relating to the management of risk. The structure of services must support interdisciplinary and interagency working and importantly the opportunity for the relevant people to share understanding and arrive at a formulation that provides an understanding of what may be predisposing to, precipitating and maintaining a particular behaviour and to structure this understanding within a sound and informed theoretical framework. Such understanding may be based around the model of applied behavioural analysis (ABA), it may be informed by the identification of co-morbid physical or mental illness that may alter the propensity to such behaviour, it may be explained by particular risks known to be associated with specific causes of a person's LD, and there may be interactional and dynamic factors within the family or the social network of the person. Where intensive and urgent assessment and intervention is required the IASS community team is also available. Admission to the IASS in-patient service is primarily where a person is mentally unwell and may be a risk to him/herself or others and that risk cannot be readily managed where he/she lives. This tends to be people with mild LD who have limited social support. Where someone is charged and/or convicted of a serious offence and the Courts are seeking guidance, admission under a hospital order to the local in-patient service may be indicated for assessment and perhaps later for treatment. Once convicted if risk is small and can be managed further work may be undertaken in the community under a probation order or community treatment order. Where a person with a LD is convicted of a serious offence and the Courts will expect a certain level of security then assessment and treatment in a secure setting may be indicated with local services remaining involved and helping to direct the assessment process.

Involvement of service users and their families

Since its inception the LDP has had a Board which has service user and carer representation and has been co-chaired by a service user. Care management and health staff in teams should ideally have close relationships with people with LD and their families and this can be another important means of collaboration between different stakeholders. Given the fact that some people with LD will be unable to communicate easily and that challenging behaviour may be maintained (rather than reduced) by the responses of those supporting them, at an individual level when assessments are being undertaken and interventions developed, these partnerships are crucial. Families and support workers are a proxy source of information. Frequently the structured collection of data by them on a daily basis

about the rates and nature of someone's behaviour, their mood etc can be crucial in determining the underlying factors that might be predisposing to, precipitating and maintaining aggression, self-injury etc. The task of the interdisciplinary team is very much to work in partnership to develop this understanding through the process of history taking, observation and formulation.

Models of care

The model outlined above was that developed in the mid 1990's with the strategic change that took place in Cambridgeshire in the south of the county with the closure of Ida Darwin Hospital as a place of social care. Its strength was that it, not only enabled the successful resettlement of people from the hospital, but with the establishment of community teams, many people were also brought back from inappropriate often secure hospital provision from out-of-area. In those parts of the county where services have been working effectively people with LD and complex needs have been largely prevented from being sent out-of-area. However, people with LD as children have, until recently, still been going out-of-area and there are still parts of the county where adults are still too often sent to hospital or residential care out-of-area for reasons that are not entirely clear. A recent review of out-of-area placements in different settings suggests that the nature and extent of specialist community support and the function and attitudes of those working in services are key determinants for the prevention of out-of-area placements. The basic model of service was agreed at the time the LDP was established in 2001. However, since then there has been concern that specialist services have been eroded and as temporary managers in the LDP have been in place changes that do not have the full support of those in the service have taken place – as outlined below the key message is that informed and supportive management and a clear vision as to what a specialist service is there to do are absolutely crucial to maintaining such a services. Experience suggests that poor local services result in greater costs. The key to moving away from assessment and treatment units is to have the necessary community teams in place and then the use of such in-patient services are reduced and when they are used it is for sound and positive reasons. Also, the only case for out-of-area hospital placement is where secure provision is genuinely needed. In the case of social care provision teams need to work through care managers and commission local living arrangements that best meet the sometimes complex needs of an individual with LD. By developing local provision and avoiding placing those with such needs in out-of-area often large and isolated social care provision the LA is better able to ensure quality, monitor the person and the service he/she is receiving, and to manage and contain costs (as pointed out in the Mansell reports).

The specialist LD services in Cambridgeshire have recently been extensively studied as part of the NIHR CLAHRC for Cambridgeshire and Peterborough and these studies have identified significant problems that have arisen since the LDP was established and health and LA personnel have been under LA management. These are now being resolved with more sound and informed leadership but

illustrate the potential complexity and fragility of such a network of services. The CLAHRC studies would indicate that key to an effective service are the recognition of the following: a) people with LD are very heterogeneous group some of whom have complex needs and that the services required must be inter-disciplinary, inter-agency, and community-based with the availability of specific additional resources.; b) such specialist services are inevitably complex and because of this complexity it is essential to have strong and positive leadership and an informed and respectful partnership and ‘design leadership’ between the LA (LDP), GP commissioning and the provider health Trusts who are together responsible for agreeing what the service is there to do and how it should be designed and function. In the absence of this there is the potential for chaos and for serious unintended consequences; c) community teams in LD inevitable work at the interface with social care services and with a multitude of social care providers as well as with families and others. Understanding this interface is critical. Whilst social care provides should be expected to provide informed and trained staff they cannot be expected to provide all the knowledge and expertise to prevent and fully support all those with complex needs due to their behaviour and/or mental ill-health – it is for this reason that community expertise and partnerships are required; d) the nature and complexity of need for some individuals is such that the expertise of different disciplines and the bringing together of different models of understanding is required. Specialist community services must be structured around a given geographic area and must be led in a manner that fosters inter-disciplinary working; e) there are cultural, legal, and conceptual differences between LA and health staff that at its best these differences bring strength to a service. However, such differences must be understood and managed – for example, the LA is under local political control and its budget determined accordingly, the NHS is free at the point of contact. There are issues around the sharing of health data and management styles and lines of accountability differ.

Conclusion

Outlined above is the model of service conceived for Cambridgeshire and which is provided to a variable degree across the county. This paper also outlines some of the problems in maintaining such a service and the importance of leadership and the understanding that an inevitably complex service such as this requires to be designed and jointly managed, recognising and respecting the roles and responsibilities of different stakeholders.

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