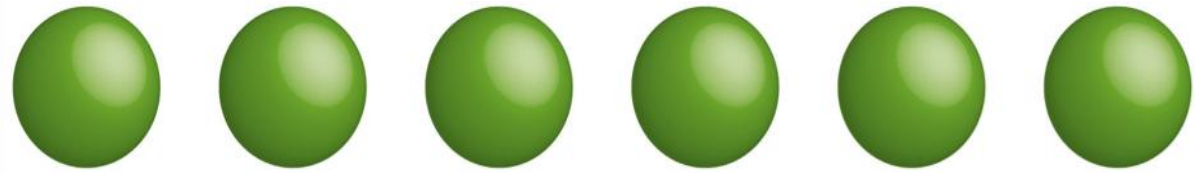
National Development Team for inclusion

Corby Clinical Commissioning Group

Nene Clinical Commissioning Group

Building Together in Northamptonshire

Alison Giraud-Saunders



National Development Team
for Inclusion

First Floor
30-32 Westgate Buildings
Bath. BA1 1EF

T: 01225 789135
F: 01225 338017

www.ndti.org.uk

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Building Together in Northamptonshire

1. Introduction

Nene and Corby Clinical Commissioning Groups (CCGs) want to improve services and supports for people with learning disabilities, including people who have mental health problems or behaviours that challenge. Over the summer (from July to September 2013) views and experiences were gathered from people with learning disabilities, family carers and staff in a range of services through a survey, easy read questionnaire and face to face meetings. Two people whose support has been personalised took part in films about the changes in their lives.

All this information was brought together and the main themes were presented at a stakeholder workshop on 19 September 2013 facilitated by the NDTi[1]. The event was attended by 62 people, including people with learning disabilities, family carers and staff from a range of health and social care services.

The purpose was two-fold:

- to check whether information gathered from the listening exercise matched the experiences of participants, or whether any important issues had been missed
- to develop ideas for action that the CCGs could take forward as part of the learning disability service re-specification and long term commissioning planning.

Participants also heard a presentation about work already under way to improve services for people with learning disabilities across the county. This includes: development of joint working between the NHS and the County Council, the 'Ordinary Living' project, and a new Quality Checker Service. A new three year plan is being developed for 2014-17.

The film stories proved extremely powerful and moving for the audience. They showed how personalising support could achieve radically improved outcomes for the individuals

[1] Alison Giraud-Saunders, Associate Consultant from the National Development Team for Inclusion

concerned. Participants suggested a number of other stories and these will be followed up so that the CCGs have a ‘bank’ of stories covering different circumstances. The films, individual stories, and easy read survey presentation are available on the Building Together information page at the following link: http://www.neneccg.nhs.uk/building-together/

2. Results of the listening exercise

The presentation summarising the results is attached as Appendix 1.

3. Ideas for action from workshop

Participants in the event on 19 September were presented with eleven themes that had arisen out of the survey feedback. They voted on what they would like to talk about and chose six topics for detailed discussion. They worked in mixed groups to develop ideas for action. They were assured that the remaining five topics would not be lost, but would be followed up in other ways. The topics chosen (not listed in priority order) were:

- things to do
- working together
- developing services
- friendships and relationships
- funding and budgets
- the role of specialist services.

3.1 Things to do

Summary: There are quite a lot of things to do in Northamptonshire, but people do not know what is available or what they can use. Supporters need to be creative to help people try new things and share resources (including transport and support). People would like a “one stop shop” (perhaps a website): what is available, quality checks, how to link up with other people interested in similar things. The Learning Disability Partnership Board and the Thera Trust have already started work on this. Supporting people into employment is particularly challenging at present and may require some different approaches.

Key points arising:

- Desire for one stop shop (perhaps a database or website) listing what is available, what it is like (quality checked)
- People would like to be able to dip in and out of activities or facilities offered by different providers, not be confined to one service

- Transport (particularly in rural areas) and staff attitudes to working evenings and weekends restrict options
- Personal profiles and care plans should include rich information about what a person enjoys to stimulate ideas about things they might like to try
- Staff need to feel supported and safe to support people to try new things and take (managed) risks, some of which will not be successful. This includes helping people to find work
- There are some structural barriers to supporting people into employment (e.g. how eligibility criteria work, interaction with benefits, interaction with transport costs and benefits such as bus passes) – these may require focused action from the council and NHS
- Employers and co-workers need support to feel confident about supporting a disabled employee (some small/medium enterprises are more responsive), including how to deal with rudeness from members of the public
- Sharing stories helps to inspire others.

Recommendations for action:

- Support the development of a virtual 'one stop shop', including the facility to share stories
- Ensure that person centred planning and service design encourage and support flexible access to a range of opportunities, including employment
- Ensure that contracts for support are clear about expectations in relation to 'things to do' and employment
- Investigate and tackle structural barriers to employment
- Ensure that contracts for supported employment include expectations in relation to support for employers and co-workers.

3.2 Working together

Summary: Tough times demand closer joint working to make the best use of resources. Health, social care and education need to work together to map resources and gaps, pool budgets and commission together to secure joined-up support that meets individual needs. People with learning disabilities and family carers need a clear message.

Key points arising:

- Health and social care need to work together to: know their population and needs; predict future demand; shape the market of services; decide together on funding and how to meet future demand
- People who use (or may use) services, family carers, providers and commissioners need to work together on this (trust in statutory services needs to be built)
- Need to move away from labels determining what service you are offered – think more widely about ways of supporting needs and tackle prejudice in services
- Customers don't care about the mechanics of integration – they just want easy access to the services they need
- Joint working has been affected by move to localities and there is frustration about duplication of efforts; improved joint working needs to include co-location, putting money together, joint assessment/review, information sharing (between different services including across transition). (New Caldicott principles support information sharing protocols)
- There are gaps in support available for some specific groups (e.g. people with profound intellectual and multiple disabilities, people on the autistic spectrum, people with Asperger's), whilst there is caution about grouping people by such labels
- Interest in developing workers with skills to work across health and social care, and across children's and adult services, to achieve common outcomes (signed up to by leaders) based on a common assessment and plan
- People with learning disabilities and family carers expect services to be honest about funding, capacity, political issues.

Recommendations for action:

- Map needs, resources and gaps to inform the Joint Strategic Needs Assessment
- Pool budgets under joint commissioning and agree a shared approach to NHS Continuing Healthcare
- Agree a model of care for the county and commission smartly to make the

best use of resources

- Involve Education in One Health Group
- Encourage networking between different services and staff groups
- Agree a clear message that people understand: “We provide a joined up service to meet individual needs”.

3.3 Developing services

Summary: There is confusion about who does what between health and social care. Improved quality and continuity of care requires an integrated pathway in which support is personalised and co-ordinated; quality standards should be set and checked by people with learning disabilities and family carers.

Key points arising:

- Not everyone knows about the services available (e.g. CTPLDs) and people are confused about which organisations are responsible for what
- Review meetings are important for continuity and to ensure information on needs is up-to-date (and support is matched to needs), but they are not happening so often
- People with learning disabilities and family carers should be in the driving seat, but want a lead co-ordinator who represents a joined up team
- Support staff need training to ensure consistent approaches to a person (e.g. in relation to their behaviour) and provider organisations need to be clear what is expected of staff
- Senior people need to listen hard to those who know a person well (especially for people who display challenging behaviour) and support person centred service design – one size does not fit all
- Quality checkers should devise standards and check services against them (including values and attitudes).

Recommendations for action:

- Develop joined up health and social care for individuals – one lead co-ordinator, one pathway

- Establish person centred service design and commissioning as a priority for people with high support needs
- Support the further development of quality checking by people with learning disabilities and family carers.

3.4 Friendships and relationships

Summary: People know some of what is needed to help people with learning disabilities widen their social circles; more 'how to' help is needed (e.g. courses) and organisational policies need to be reviewed to ensure they support such ways of working.

Key points arising:

- Information about activities is widely available (e.g. libraries, newspapers, radio) – use what's out there
- People have skills and talents they could share (like through timebanking)
- Focus on shared interests can help to build relationships irrespective of ability
- Some organisations have an explicit ethos of equality (e.g. Steiner, Camphill) – look at how this could be encouraged
- Start in schools, e.g. Duke of Edinburgh awards
- Family carers and support staff can be isolated too – look at creative ways of involving people together (e.g. 'Come dine with me')
- Mentoring or buddying can help people give something a go
- Some people need specific training in using IT (including keeping safe online)
- Person centred service design needs to take account of the costs of activities for supporters (where they can't go free) and contracts for support need to clarify expectations about flexible support (so activities aren't determined by shifts) and increased responsibilities (impact on pay rates)
- Need to learn from good practice elsewhere.

Recommendations for action:

- Offer training on developing friendships (including keeping safe) based on similar interests
- Develop a website to share information on similar interests.

3.5 Funding and budgets

Summary: Too much time and energy goes into 'policing' boundaries (between commissioning organisations, and between providers). People with learning disabilities and family carers would feel more confidence in assessors if they were independent of funding agencies; one person-centred pathway supported by joint funding is needed to make best use of resources.

Key points arising:

- Better use could be made of existing resources if health and social care funding was joined up, if providers were encouraged to collaborate, if individuals were supported to consider pooling resources, and if resources followed the person (e.g. in and out of different settings)
- Some people need improved access to advocacy in order to ensure they are receiving all their entitlements and are making best use of all their resources
- People with learning disabilities and family carers would feel more confidence in assessments if they felt these were independent of decisions about which agency would fund support
- Person centred service design needs to take account of the costs of activities as well as support.

Recommendations for action:

- Health and social care commissioners work together to establish joint budgets supporting a single pathway
- Explore the option of independent assessment and brokerage
- Encourage collaboration between service providers to increase the range of activities available

- Agree protocols between health and social care about funding for support whilst someone is in hospital.

3.6 The role of specialist services

Summary: Early, joined up interventions to prevent and manage crises from childhood onwards could reduce demand in future for crisis in-patient placements. Getting to know and understand people who are currently placed miles away, so that alternative support can be designed and set up, can be difficult: a transitional service is needed with an explicit focus on supporting such moves.

Key points arising:

- Current gaps include early intervention, joint working, a (joint) 'responsible person' and creative approaches that include positive risk management
- More community support options needed for people whose behaviour is seen as very difficult, to enable them to move out of the family home or back from out of area
- CTPLD resources need to match the development of community support, so that they can provide the back-up required in collaboration with other professionals (using agreed pathways)
- Specialist support is also needed to work with children, in collaboration with CAMHS
- Specialist support is also needed to work with parents with learning disabilities to support them to keep their children.

Recommendations for action:

- Ensure that annual health checks cover mental health and dementia properly
- Ensure that the service specification for CTPLDs includes the support they need to give families and services to improve early intervention and sustained support for individuals, in addition to direct interventions with individuals whose behaviour challenges
- Ensure that protocols for joint working are in place with other services (e.g. CAMHS, maternity, children's services)
- Develop local transitional services (e.g. up to 18 months) to support people to move from more restrictive settings (whether in or out of county); this could include a step-down service.

4. Topics that were not chosen to be discussed on the day

4.1 Service providers

While some services are valued, a number of comments indicated the need for proactive market development to ensure that providers are clear about the range of services wanted and that appropriate new entrants (including small and micro providers) are encouraged. Workforce development should be tailored to the needs of people receiving support (now and in the future) and collaborative working needs to be improved to ensure competent and confident responses to people with the most challenging needs. Quality checking should be focused on outcomes and combine the skills and perspectives of people with learning disabilities and family carers with those of the commissioning bodies.

4.2 Independence

Housing was cited in many comments as a key enabler of independence (which was not interpreted as necessarily meaning living alone). A strong strategic approach is needed across health, social care, housing authorities and housing providers (such as housing associations and private landlords) to ensure the availability of a range of options.

4.3 Influence

Whilst one comment suggested that “services are starting to listen more”, the majority of comments indicated that respondents did not feel influential, despite being consulted. A specific concern for some people was lack of independent advocacy (both for people with learning disabilities and for family carers).

4.4 Information

Comments on information fell into two groups:

- demand for accessible information, and effective library management so that

available information is kept up-to-date and everyone knows where to find it

- demand for a detailed ‘directory’ about what is available across the county, including small local groups and services – again, kept up-to-date and readily accessible.

4.5 Communication

The majority of comments about communication focused on the challenges of communicating effectively across teams and services and organisations, especially at a time of rapid change in several sectors. Personal connections help, but more systematic communication links are needed too.

5. Overall priorities for action and recommendations to commissioners

A number of common themes emerged from all the comments and discussions. These are summarised below as priorities for action.

5.1 Joint working

There was a clear and strongly expressed wish for all the partner organisations to work together - with people with learning disabilities and family carers at the heart of that joint working (supported by advocacy as necessary). The aim should be a common purpose: “A joined up service to meet individual needs”.

The priorities for joint working can be summarised as:

- between commissioning organisations (principally health and social care, with housing and education partners)
- between health and social care practitioners
- between service providers, collaborating to offer access to a wider range of support and opportunities
- across these different groups, sharing ideas to make best use of scarce resources.

Specific recommendations:

- Establish joint commissioning with a pooled budget; resolve how NHS Continuing Healthcare is to work as part of this
- Create a robust Joint Strategic Needs Assessment to guide future commissioning
- Agree integrated pathway(s) and lead co-ordinator arrangements.

5.2 Personalised support

To achieve personalised support that promotes independence, the joint working arrangements advocated above should include:

- person centred profiles and plans that include rich information about individual interests and talents
- flexible access to a range of services and opportunities, with support that can follow the person into different settings
- organisational policies that support such flexibility and positive approaches to risk.

Specific recommendations:

- Review local approaches to person centred assessment and planning
- Review contractual arrangements with services to ensure that these support personalisation
- Explore the options for user led and/or other independent forms of assessment, brokerage and support for personal budgets and personal health budgets
- Review local approaches to market development and workforce development to ensure they support personalisation.

5.3 Information

Specific recommendations:

- Develop a local library of information about services, supports, amenities and opportunities; this should be accessible in a variety of ways (including to people who do not use computers). Ideally this would incorporate a 'TripAdvisor©' type of function that would allow people to post reviews and share experiences
- Explore ways of linking up with people with common interests (possibly linked to the library of information).

5.4 Support to make change happen

Whilst there was a lot of agreement about the kinds of changes that people would like to see, many also commented that they would need help to achieve this.

Specific recommendations:

- Gather and share a wide range of stories (possibly linked to the library of information) to inspire and encourage others
- Offer specific 'how to' support linked to priority developments, e.g. how to go about helping people to develop relationships
- Build up quality checking, focused on outcomes, that involves experts by experience
- Jointly review structural barriers to personalisation and to employment and initiate corporate action where appropriate.

5.5 Early and lifetime specialist support

The priority areas identified for action, in addition to the joint working described above, were:

- early support and interventions with children and young people to prevent problems in later life
- continuing support to families to prevent and manage crises
- a range of options for housing and skilled support
- transitional support for people leaving restrictive settings.

Specific recommendations:

- Use the review of the specialist services specification to address the NHS contributions to these priorities
- Use the joint working arrangements advocated in 5.1 above to build on the 'whole systems' approach to support for people with high support needs (already a focus of the 'Ordinary Living' project).

6. What happens next?

Nene and Corby Clinical Commissioning Groups (the CCGs) will take this report to the Joint Commissioning and Health and Wellbeing Boards to advise of the recommendations identified within the Building Together listening exercise. The CCGs will work with Northamptonshire County Council to write a three year strategy and action plan from the recommendations.