

Feedback from the notes taken at the Learning Disability Engagement Events in February and March 2018.

GRANTHAM (Tuesday 6 February)

Working well

- Care closer to home for people reduces anxiety and is welcome.
- Familiarity of environment is ideal.
- Care at home helps with travel given Lincolnshire geography.
- The behavioural team will go to educational settings to undertake assessments.
- Annual health check offering is working well in some areas – however need consistency.
- CAMHS working well once you've managed to get into the service.
- Comment from Healthwatch that they offer a signposting service.

Challenges/Gaps

- LD service not commissioned to diagnose LD.
- Carers don't always have easy access to referral forms.
- Once people receive a diagnosis of ASD there is no follow up service! Carer is then left to deal with it.
- Gap in services for people who have a diagnosis of autism but no diagnosis of a learning disability.
- We would like integrated services for people with autism so that people get the service they need.
- The split between health and social care services does not help to create seamless services. (Social care colleagues do not attend MDT meetings.)
- Transition points need signposting; who to contact next!

Suggestions/Concerns

- Carers first in every hospital CSAC (Carers Support and Assessment Co-ordinator) to be a present for people needing support; advice with welfare and benefits.
- Accessible information needed; sharing information; signposting.
- Adult autism:
 - People with autism may not have a learning disability.
 - Presentation talks about assessing and signposting – but nowhere to signpost to?
 - Reasonable adjustment is a good principle (e.g. access to mental health services) but we need a service to meet the needs of childhood and adult autism.
- LPFT staff teams need training on what is available for people – benefits etc.
- Emergency plan format (akin to passport mentioned at Spalding meeting) would be helpful – information and signposting.
- Needs to be a clear understanding that LD is separate to MH, not the same.
- Need to make sure people with LD/parents/carers are aware that they are entitled to an annual health check. Should be generated through the GP.
- Access to physical health services for people with LD – how?

- LCC services – why are LD day services chargeable? If a person has an addiction then they don't have to pay. Discrimination?
- Not everyone (staff) knows what is happening/available. Need a 'one stop' directory. Advertise service more broadly.
- Need a service to link services – broker access to services that a person may need. (as mentioned at Spalding) Co-ordinate library of support.
- Collaborative working across services is needed.
- Plan format for if person is in hospital/on own – this is what I like; this is what I don't like; please communicate with me by (Similar to passport mentioned at Spalding).
- Have a plan should something bad happen or person is left on their own (possibly through bereavement – death of carer/parent). Not having to wait for access until something bad has happened.
- Would be great if places could be made LD friendly!

Grantham - Feedback Overview

Table 1

1. LD services are a broken jigsaw/needs pulling together.
2. People do not know where to go for help.
3. Staff do not always know where to signpost people to.
4. Key message: fractured services/need to join gaps.
5. Need backup/preparation and planning.
6. Everybody refers you on People get passed around.

Table 2 (Carers First)

1. A theme of how we share information and help people understand how people get access.
2. Referral forms: how do people get access to the service?
3. Build alliances and partnerships.
4. If a person receives a diagnosis of autism: what happens next?

Table 3

1. Better to have people seen in their own homes.
2. Integrated services should be built.
3. Where is the service for people with autism?
4. Lots of people with autism out there who do not have a service.

General Feedback

1. LD assessment member of staff says this is not commissioned.
2. For young people what is the relationship with the education system?
3. Network for people with LD/carers – is there a register of people?
4. These types of events give people with LD a voice.
5. Create a network to give people with LD a place and voice in society.
6. Good for raising awareness.
7. Bring in the business community.
8. Would like LD friendly places.

SPALDING (Wednesday 7 February 2018)

Working well

- Community model seems to be an improvement.

Challenges/Gaps

- Frustrating when move from child to adult services – access seems slow to be able to get support. For example, SALT services – working through backlog and need to get to waiting list. (Looking at providing Makaton training via intervention workers.)
- Transition from child to adult services is a time of stress for families. This is social services – could NHS be part of this more?
- Consideration of parents/carers views even when the person with LD becomes an adult. Very few people can give consent or override once person becomes an adult.

Suggestions/Concerns

- Could a member of LPFT be present at last transition meeting when a young person transfers from CAMHS to adult services? To identify support. Feel quite supported in children's services but feel on own above 18. More of a hand hold transfer would be helpful.
- Lack of consistency with social workers. Lack of consistency with support – re-assessment when reach adult services can result in loss of support whilst needs haven't changed.
- Services should be working for the person with the person and their needs at the centre.
- Need greater/better liaison between services – it is important social care links up.
- People want to know who's who and different roles and who to approach for help. Parents would like directory of services/leaflet on who to approach. There is going to be an online library of services but don't know what services it will reference, clarify and signpost. Note: LCC are doing this but it is still at the tendering process.
- Idea of brokerage services – a broker who would identify and broker services for individual who would be employed using personal budget.
- Annual health check – GPs responsibility to provide this. If GP surgery doesn't provide then can be supported to go to/approach another GP for it. People with LD can now get this when they turn 14. Are all parents/carers/service users aware of this?
- Is there a possibility of LD specialist (health liaison nurse) on call at A&E – hospital services?
- Would be useful to have a passport for person to take with them to hospital describing them and how to care for, speak to, and interact with them.
- **Keep the person with LD at the centre of the plan.**

Spalding – Feedback Overview*

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| 1. Passport for people to help services understand and meet their needs. |
| 2. Greater liaison between services, especially when person goes from child to adult services. |
| 3. Directory of services so parents/carers know who's who and who to contact. Keep person with LD at centre of any plan for their care. |
| 4. Consistency with support and assessment is necessary. |

*Only one table due to numbers

BOSTON (Wednesday 21 February)

Working well

- New hub teams are working well. (two different tables)
- SPA number is being used and given out by GPs.
- Better outcomes.
- Good communication.
- Cutting down waiting times.
- Multi-Disciplinary support team is welcome.
- Away Day – could be an opportunity to ensure everyone is working the same way.
- Team feels model of service is better than before because people can make things happen e.g. physiotherapy assessment.

Challenges/Gaps

- What is out there?
- ASD – diagnosis, support post diagnosis, when it is ‘none MH problems’.
- Signpost to MH services.
- No service for people with autism – big gap.
- No access to SALT for youngsters with a diagnosis of autism. This is so important.
- Advocacy support for carers who have autism – Care Act specifies this should be in place.
- People with lived experience providing support e.g. with/for benefits advice.
- Gaps in autism services – GPs – Hospitals – Services.

Suggestions/Concerns

- Challenge – getting everyone/services to work together. Size of County and diversity is a challenge.
- Waiting times and referral times can be inconsistent – long.
- Mobility referral – forms much more person friendly now. Communication section is good and like the picture format.
- Response to referral to say that the team has received them would be helpful.
- Concern regarding Long Leys closure over access to beds when someone is in crisis. People are already told there are no beds. Have to be ‘nearly dead or killed yourself’ before you get a bed – would be better to have a bed before it gets that bad. Does agree however that it is better for people to be cared for in their own home but that depends on who is around them.
- Day services and day centres are closing down thus reducing provision for people with LD.
- Leisure services which ran alongside MH/LD services seem to have ceased. Socialisation is helpful and important and this is being cut back/lost.
- Need services signposting/sharing.
- Need to publicise health liaison services/nurse in hospitals.
- When someone is in real crisis relationships between all teams isn’t helpful – they are not talking to one another, don’t know who there is to deal with/support people.
- Relationships need to be improved across these sectors.
- Immediate crisis seems to mean that someone has to make ‘a thousand phone calls’ to get help. **Gaps in provision.**
- There needs to be a clear pathway of who to contact and who can support.
- Needs to be a greater understanding of what the term Learning Disability means.
- Spend lots of time phoning police, SPA, ambulance and being passed from one to the next. It is so difficult to get help. Getting the right help can be difficult.
- Need the right help at the right time.

- Services in A&E for people with LD need to be better. Example: lady with LD sent home from A&E with meds in a taxi to return to supported living and couldn't get in. Hadn't been asked any questions about their return to home/who would be there.
- Need to link in with others e.g. GPs
- Team managing risk.
- Information to be provided in a way that is easy to understand e.g. GP practices, police, needs to be 'LD friendly'.
- Awareness day for GPs surgeries.
- Talk to carers and service users.
- Improve how we link more services together.
- Working link with community hubs e.g. GP practices – advice about who to refer to.
- Social health – signposting for ASD, for LD when 14+ - children's - adult and transition.
- Didn't know about CHAT.
- ASD – can help to access MH services.
- MH services – adapt services to meet ASD needs.
- Problems with carers for someone with a husband with dementia and LD. Person was advised that they speak to GPs regarding carers.
- Some need help at carer's reviews as sometimes they (reviewers) said that people can work or use a bus. (Some can get 2 steps down the road and would not know where they are) so can't work.
- Services are not joined up .
- How do we work with autism charities?
- Support for carers in Boston not working well.
- A bit of time off for people with intense caring responsibilities. What if a carer is ill? Meetings/paperwork burden of caring responsibilities.
- There is nothing to give people a rest.
- Would like directory of what is available.
- How we communicate with each other/being non-judgmental.
- Signposting to services available for carers as don't know what is out there.
- SALT – (carers) for people with autism. Need an explanation about why services are not available in a language that is accessible.
- Short break for carers important. Support for families who have several people they are caring for.
- Stigma for people with autism; raise awareness about behavioural challenges. Educating the public. Is the video stage managed?

Boston – Feedback Overview

Table 1

1. Signposting people to the right service could improve.
2. Clear pathways of where to go in crisis are needed.
3. Clearer understanding of people with a LD and their needs to help people thrive.
4. Where to go to get the right care is not always clear.

Table 2.

1. Strong focus on huge gap within autism.
2. Big gaps in carer support/need better support.
3. Stigma/raising awareness.
4. Some families supporting several people.
5. Lack of integration/partnership/working together.

| Table 3 |
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| 1. How to get information about LD services to GPs. |
| 2. How do we partner with primary care? |
| 3. Could we come out and speak with communities more often. |
| 4. Teams are working well. |
| 5. Communication is better. |
| 6. Waiting times reduced. |
| 7. Community response better. |
| 8. Big gaps in autism services. |
| 9. CHAT response has been very good, however there was an observation that it is sometimes difficult to cope when a person is harming themselves and a concern that whilst the community service is good, sometimes a place of safety may be required. |

LINCOLN (Tuesday 6 March)

Working well

- Liaison Nurses – highly supportive, continuous support offered
- Integrated working – maximised independence, got me in work
- GP Support, ULHT nurses brilliant
- PEER Support roles / experts-by-experience roles
- Organisations in place are doing good work and supporting – these are few and far between e.g. Warren Wood School.
- Communication at a service level becoming more the ‘norm’ and effective.
- Mainstream services (certainly outpatients) have been excellent and reasonable adjustments made.
- Value what service users think is working well.
- Good that we encourage staying at home - more sustainable.

Challenges/Gaps

- Criteria for access is very robust. IQ related instead of case-by-case.
- Challenges for people with ASD, or carers of people with ASD, appear highly functioning people, not obviously someone with a need but they are.
- “Learning Disabilities only”, restrictive, unhelpful.
- More work needed with other health services to reduce inequality and ensure high standard of care across all localities.
- Blood monitoring device in community – maximises independence.
- Feeling that some treatments are “exclusive” only to people with Learning Disabilities , even though someone with ASD has the same need - discriminate.
- Access to mainstream services for people with ASD.
- Sensory profiling.
- OVER PRESCRIPTION - STOMP – planning ahead, support from hub beforehand, CHAT support.
- Pre-support before medication is reduced – risk assessing?
- Dementia Identification. All staff awareness of signs and symptoms of dementia in people with a learning disability.
- Ways to advertise the LD hubs. GP surgeries annual health checks? Chemists.
- A named person for a family/carer to go to as a liaison – person who if they didn’t know would find out.

- Information should be shared with all experts and professionals involved in person's care – MOSAIC – access increasing.
- Because commissioning system is changing – services are changing/disappearing and it can be difficult to keep up.
- Need support when it is required not within set timeframe or number of sessions.
- People don't always know the difference between services and what they can offer, continuing care for example; better partnerships, working together, building bridges.
- STOMP – linking with physical health.
- Active support for people with a disability – how do we work together to access more activities.
- Can we refer if we are worried about someone? Will we be listened to?
- People find themselves in a void.
- Lack of training in organisations.
- ASD not understood, especially in employment.
- "Parents get an ASD diagnosis and think it will change everything tomorrow." Wider than LD.
- Challenges to deliver in rural county. (Linked to ASD services also.)

Suggestions/Concerns

- Group work is not suitable for everyone and not effective for some people.
- Understanding individual needs and diagnosis.
- Social Care aspects of model, feeling unsupportive, lack of support evident and felt
- Recognise that ASD and Learning Disabilities are closely linked, stop fighting it and make them as accessible as each other.
- Referral process to LD. Specialist service from GP?
- Positive behaviour support training for private providers for families/carer groups as a preventative measure. (For children <18 there is the Healthy Minds (CAMHS) since 1st Oct 2017). Linkage would find this very useful.
- Monthly email bulletin for people who want to receive information on services/update on LD services.
- 'Hands on' family/carers who are doing everything can be bypassed by the service as they are managing themselves/doing it themselves. Difficult to get balance and 'let go' to allow person to flourish and access services. Equally wanting to protect them.
- Online forum for parents/carers.
- Disseminating information to those who need to know.
- Finding out about these events in the first place if not on contact list.
- Transition is an issue: starts too late for child to adult services – could it be 14+ and not 17?; falls away >25 'cliff edge' when become an adult.
- Lead time from things being identified/suggested to actually happening.
- Signposting – knowing who to turn to, especially >25.
- Don't want to be passed around.
- Referral form not user friendly, difficult to fill in, can feel threatening. Would be helpful if form had on 'If you need help filling in this form contact...' Form needs to feel more 'humanised'. Needs to be clearer who is filling it out – person or carers.
- LD is a term that covers a broad spectrum. Where people have profound LD, support seems/is very poor/unsupported.
- Recognise family members as 'experts by experience' – especially when a person is an inpatient.
- Transition can feel like 'passing parcels'.
- Reasonable adjustments needed for those accessing mainstream services.
- Stimulate provider market.

- Physical activities linked to each hub team? Sponsored by LPFT/LCC. Physical activities LCC partnering.
- NHSE hub – NHS will not take inpatients into NHS care because of transforming care agenda.
- What is available and what is provided by partners in health, social care, vol. sector, other organisations – people do not know what is out there – we need a directory, signposting, and website. SHINE?
- Transition to adult services is not smooth – 14 yrs. refer to CHC for transition; 16 yrs. preliminary assessment; 18 yrs. smooth transition. Organisations not working together.
- Dietician – is there a service in the community teams (no) – how do we work together on physical healthcare within LCHS, CHC.
- Professional challenge – reflective practise – doing things in our traditional ways.
- Too much ‘doing to’ in the past, not doing with, is getting better but much improvement required.
- Learning how to listen – we often don’t, we tend to steer.
- We need to learn to share power/listen/question. Listen to patients – all sectors.
- Wider issue – person centred.
- Keep up to date with changes/networking.
- Autism – big gap – no services to support diagnosis.
- ASD services are delivered in other areas in the country (housing, employment benefits, welfare rights, life skills, and support at hearings). This is needed in Lincolnshire.

NOTE: Agreed in principle that the new community service is better – however not much knowledge of previous service.

| Lincoln – Feedback Overview | | | | | | | | |
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| Table 1 | | | | | | | | |
| 1. Big gap in Lincolnshire for Autism. | | | | | | | | |
| 2. Families have no support and think diagnosis of Autism will help (but it doesn’t). | | | | | | | | |
| 3. Employment opportunities for people with Autism = needed in Lincolnshire. | | | | | | | | |
| 4. Community model is good but we need to learn how to <u>listen</u> to people <u>better</u> . | | | | | | | | |
| 5. Really good that people are seen in their own homes under the new LD community model. | | | | | | | | |
| Table 2 | | | | | | | | |
| 1. Physical activities are needed for people with learning disabilities. | | | | | | | | |
| 2. Transitions are not yet right. | | | | | | | | |
| 3. We don’t know what services are available for people across the board – please help. | | | | | | | | |
| 4. Need integrated services where people cross agencies. | | | | | | | | |
| 5. Big gaps in autism services. | | | | | | | | |
| 6. Physical activity needs to be encouraged strongly. | | | | | | | | |
| Table 3 | | | | | | | | |
| 1. People need to know about the services available at LPFT: not advertised. | | | | | | | | |
| 2. Medication – when reduced please support us more and plan forward for possible impact. | | | | | | | | |
| 3. Like the focus on reducing medication. | | | | | | | | |
| 4. People with a learning disability are living longer/need to recognise when people with learning disabilities are developing dementia. | | | | | | | | |
| 5. Positive behavioural support training should be available. | | | | | | | | |
| 6. What is available for children and young people? | | | | | | | | |
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| | Church / chaplaincy / spirituality | | | | | | | |

| Table 4 |
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| 1. GP support, ULHT nurses brilliant, expert by experience, PSW roles all working well. |
| 2. Understanding individual needs, diagnosis, and available treatment and recognising and supporting the needs of people with ASD. |
| 3. Social care appears to be lacking with a feeling by people that they are not supported. |
| 4. "Learning Disabilities only" is restrictive and unhelpful; support lacking for people with ASD who appear to be functioning well. |
| 5. Consistency in standards of care needs to be apparent across all localities. |
| 6. Post diagnosis support for people with ASD is a KEY DEVELOPMENT NEED! |
| Table 5 |
| 1. Generally good development with the new model. |
| 2. More information is being shared in events like this but if you are not on the contact list how do you become aware of them? |
| 3. Transitions are a weakness – "post 25 years old you fall off a cliff edge". |
| 4. Lead time it takes for things to happen. |
| 5. Named person to go to, to navigate/who do I go to next? |
| 6. Information about the person should be shared with relevant professionals. |
| 7. Sometimes people are passed around from one service/professional to the next. |
| 8. Help with filling in referral forms for single point of access (SPA) – make forms more humanised. |
| 9. Please recognise family as 'experts by experience' too. |
| 10. It is difficult to keep up as things are changing so quickly. |
| 11. Please create an online forum and a special LD bulletin. |

SKEGNESS (Wednesday 21 March)

Working well

- Wellbeing service supports people with LD with housing, PIP forms etc.
- Engagement events allowing opportunities to get conversations going between organisations about what we all do/ what we offer.
- CHAT team is helpful and supportive when people are in crisis.

Challenges/Gaps

- Let's talk to each other.
- How other agencies e.g. Job Centre can refer people in crisis – DWP in Skegness going into Marisco (GP surgery Mablethorpe) once a week and having a very positive impact on mental health through supporting people to find work.
- Limited service/large gaps in service for people with ADHD and autism.
- Linking up different services and integrating them; social, health, third sector.
- Knowing what is available.
- Knowing where to go for information about how to get in to services. (ELDC - East Lindsey site for what is available).
- Major life events and change, particularly grief and loss, family members
- **Please listen to me**
- It takes a long time to get a diagnosis.
- Lack of support to help people with an understanding of their own LD needs.
- Gaps between crisis team and LD services – if fall between services. Trying to get help can feel more stressful than the crisis itself at times.
- Don't know who to ask and what to ask for – what services are there?

Suggestions/Concerns

- Share information between teams so that I do not have to repeat my story over and over again.
- Seeing different people all the time and having to repeat my story makes it worse.
- Person saw a different person in crisis team and had to repeat themselves; needed help to control anger and having to repeat story over and over makes it worse.
- CHAT – important to be able to get in touch with someone quickly.
- Want services to become better connected to each other.
- Raise awareness of LD services.
- Share best practice
- Raise awareness of better mental health.
- Input into people's care that addresses social issues.
- People need compassion, dignity and respect.
- When a person has LD it can be hard enough to focus on their own needs and can be difficult to think of others/ may not be aware of others feelings.
- Better if services worked together, shared information and talked to one another.
- Lack of services for people with Autism, ADHD.
- How are families and service users supported to find out about LD services?
- People are being passed around between services; distressing.
- Better if for organisations that support people they have information on where to go and who to go to get help.
- Individuals can feel that their health needs are being decided by professionals who have never met them.
- A question was asked about the difference between CHAT and crisis team. This was explained.

| Skegness – Feedback Overview |
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| 1. Services need to work together and talk to one another. Having to repeat your story is not helpful for wellbeing. |
| 2. Where can people get information on services, what is available and who to contact? |
| 3. Please listen to the service user. |
| 4. Being passed from one professional and service to another is not helpful. Want consistency where possible. |
| 5. Support for people with LD in crisis can be lacking if they are not deemed to have 'severe' enough needs for services. |