



LINKAGE
Community Trust

Out Of The Shadows

A report into the mental health
needs of adults with learning
disabilities in Lincolnshire.
February 2014

About Linkage Community Trust

Linkage Community trust is a national charity based in Lincolnshire, which delivers high quality specialist education, care and employment support services for young people and adults with learning disabilities. Its 38-year history has established Linkage as a major provider in delivering flexible services which promote personal autonomy, independence and achievement. Our aim is to ensure that people with learning disabilities have the same rights and opportunities for inclusion, fulfilment and feeling valued in society as everyone else.

Linkage College is the longest-established specialist further education college of its type in the country. It accommodates both residential and day students at our Lincolnshire and North East Lincolnshire campuses, aged primarily between 16 and 25. Linkage Care Services offer residential care, supported accommodation and short break facilities in more than 70 properties across the county and beyond. Our Employment Services work in partnership with more than 140 employers to support learning disabled people into meaningful and sustainable work.

Acknowledgements

We would like to thank all the individuals across Lincolnshire who completed our 'Bridging the Gap' survey and shared their views and stories, as well as the many families and carers who have also told us about their experiences and their opinions about current mental health services.

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Foreword

Mental health is everyone's business. It is a recognised fact that in any one year, 1 in 4 of us will experience mental health difficulties. However, for people with learning disabilities, the incidence of mental health difficulties is much higher – affecting between 25% and 40% of people.¹

- Studies have shown that for children and young people, the prevalence rate of a diagnosable psychiatric disorder is 36% in children and adolescents with learning disabilities, compared with 8% of those who do not have a learning disability.
- We also know that the prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% compared with 5.7% aged 65+) and that people with Down's syndrome are at particularly high risk of developing dementia.
- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% compared with 1%).
- Challenging behaviours are shown by 10% - 15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49.

Primary care data collected from GP clinical systems in Lincolnshire² reinforce the greater risks of mental ill health faced by young people and adults with learning disabilities.

We also know that extrinsic factors such as poverty, lack of employment, social isolation, barriers to accessing services including health services and public transport, are all factors more likely to be experienced by this vulnerable section of the population – and more likely to impact negatively on individual health and wellbeing.

It is in this context that Linkage Community Trust - funded by Lincolnshire's Mental Illness Prevention Fund - embarked upon a piece of primary research to investigate the mental health needs of adults with learning disabilities and to find out their experiences and expectations of mental health services. We aimed to determine what works and what doesn't work for the individuals involved and to use this information to identify some key findings to inform the current and future development of services.

¹ Foundation for People with Learning Disabilities, 2014. www.learningdisabilities.org.uk

² A health needs assessment for adults with a learning disability in Lincolnshire, NHS Lincolnshire, 2012

Future population estimates indicate that there will be nearly 8 million more adults in the UK by 2030 – with a concomitant increase in some 2 million more adults with mental health problems than is the case today. In Lincolnshire, this translates into an estimated increase in the number of adults with learning disabilities from 10,434 in 2014 to 10,774 by 2020, with an associated increase in adults aged 65 and over with learning disabilities from 3432 in 2014 to 3926 by 2020.³

If the projected data is correct, the overall increase in the number of adults over 18 with a learning disability will have increased by 16.3% between 2011 and 2030 to a total of 15,474.

This makes it all the more necessary that everyone who needs mental health support and care should get the right support at the earliest possible opportunity and is supported to be able to lead a lifestyle that maintains their emotional wellbeing and wellness.



A handwritten signature in black ink that reads "Ges Roulstone".

Ges Roulstone
Chief Executive, Linkage Community Trust

³ JSNA Overview Update Report 2013, Lincolnshire County Council

Key Findings and Recommendations

Our findings showed that many adults with learning disabilities in Lincolnshire are 'living in the shadows' by comparison with their non-disabled peers – that they don't or cannot participate in community life to the same extent; that they don't or cannot access health services and other support services to the same extent; that they don't or cannot work or access volunteering opportunities to the same extent and that they don't have the same 'fit' with the mental health support services on offer and accessed by their peers. Some have given up trying. Others are encouraged to keep going by family and friends. Others still, fall under the radar, some of whom may not be known to their local GP surgery and who may therefore have undisclosed and unmet needs.

One woman told us: 'Not being able to do something when you are on the cusp of doing something means that you constantly miss out as you do something well below your capabilities.'

She spoke of:

- Nearly but not quite achieving
- Nearly but not quite succeeding
- Nearly but not quite able to access services
- Nearly but not quite gaining opportunities
- Nearly but not quite moving on.

On behalf of these individuals, Linkage Community Trust is calling for solution-focused approaches to developing better and more integrated services for these individuals to support and maintain their mental health and wellbeing, which include the following:

- a holistic response from professionals to support their mental health needs;
- guidance, support and signposting with consistent support from the point of referral;
- a greater awareness and understanding of learning disability, including autism, by healthcare and associated professionals, particularly frontline staff – who should make health care environments, including GP surgeries, more welcoming and accessible for individuals and who can recognise and address the different communication needs of patients;
- a greater awareness of learning disability, including autism, amongst members of the emergency services so they can more effectively recognise and deal with situations in which individuals may express distressing or challenging behaviour;
- a greater awareness and understanding of the impact of cuts to services on the mental health and wellbeing of the individuals concerned and their families and carers;
- more consistently-funded 'light-touch' enablement support to individuals through community-based projects, which can offer a lifeline to maintain community connections and friendships, whilst helping develop skills, self-esteem and resilience;
- better personalisation of services which are developed and delivered in partnership with service users, who are recognised and valued as 'experts through experience.'

Aspirations for the Future

1. Lincolnshire Partnership NHS Foundation Trust should research and develop the model of 'light-touch' enablement support in partnership with Managed Care Network partners, such as the Get More Confidence programme, as an effective and cost-efficient method of supporting individuals with low-level mental health support needs and those at risk of developing mental ill health.
2. Community-based projects that are shown to be delivering effective non-statutory mental health support services within the Managed Care Network should continue to be funded through mental illness prevention monies, including services which involve peer support.
3. Awareness of learning disability, including autism, is raised in statutory organisations across Lincolnshire, particularly amongst frontline services and emergency services. More detailed training should be made available to these staff in how to communicate effectively with individuals who communicate differently.
4. Lincolnshire Partnership NHS Foundation Trust's commitment to a Single Point of Access as its new referral channel that accesses all mental health, learning disability and drug and alcohol recovery services is welcomed and should be further developed through incorporating service users' views and experiences. Information should be accessible to all service users, incorporating use of Easy Read.
5. Staff in emergency services should be better resourced to deal with adults with learning disabilities who express distressing or challenging behaviour so that an appropriate response can be made which does not escalate a situation unnecessarily. A 'street triage' service – involving trained mental health professionals working with police officers as a first-line response – being piloted in several local authority areas, including Lincolnshire, should be further developed as a co-ordinated approach to deliver a more effective crisis response.
6. Joint plans should be developed to meet the likely increased demand from the increasing number of adults (including older adults) with learning disabilities and mental health needs and young people transitioning from child to adult learning disability services.
7. Regular feedback should be provided on the progress made by the Lincolnshire Clinical Commissioning Groups in meeting the recommendations of the 2012 health needs assessment report for adults with a learning disability in Lincolnshire, which included, inter alia:

- All GP practices should be supported to provide annual health checks and a health action plan to all people with learning disabilities in Lincolnshire known to local authority services and / or primary care. The uptake and quality of health checks and health action plans should be monitored.
 - Ensure all commissioned services (including primary care, community-based and hospital-based services) are accessible by people with learning disabilities where possible and that reasonable adjustments are made to support access and uptake of these services.
 - Protocols used to identify adults with learning disabilities in the criminal justice system in Lincolnshire should be reviewed to confirm if they are being identified and cared for appropriately.
 - Equality impact assessments should be completed for all existing statutory services and regularly reviewed to ensure that reasonable adjustments are required and have been made to support access for people with learning disabilities to these services.
 - Clinical commissioning arrangements should include strong representation from service users with learning disabilities to improve transparency of decision-making, accountability and engagement of the local community.
 - A shared policy between statutory services in Lincolnshire should be developed on facilitating a person-centred communication approach with learning disability service users who have limited or non-verbal communication.
 - There should be a clear pathway between mental health services and learning disability services so that people with learning disabilities are not passed from pillar to post between services.
8. The My Choice My Care adult social care directory on Lincolnshire County Council's website should be further developed to provide an online source of information regarding learning difficulties and disabilities, including autism, with dedicated webpages for people to access and seek necessary support. This information should also be accessible for people who do not have online access or are unable to use it.
9. Lincolnshire County Council and Lincolnshire Partnership NHS Foundation Trust should support the development of assistive / augmentative technologies in mental health, palliative and community care settings, to support the wellbeing and confidence of adults (including older adults) with learning disabilities and mental health needs, including dementia.
10. The Green Light Toolkit 2013 (National Development Team for inclusion) which is a guide to auditing and improving mental health services so that they are effective in supporting people with autism and people with learning disabilities, should inform local service review and delivery.

- 11.** More effective transitions should be in place for young people with mental health needs reaching 18 and transitioning in to adult services to avoid the 'cliff-edge' situation where young people become lost to the system when they reach adulthood.

- 12.** Mental health should be accorded the same focus as physical health in plans for joined up health and care through the Health and Wellbeing Boards to support the integration of physical and mental health care and social care.

Methodology and Rationale

Various methods were used to gather information and evidence for this research.

These included:

- Working with community partners to identify and make transparent the personal experience and mental health needs of adults with learning disabilities in Lincolnshire.
- Desk-based literature research.
- Liaising / meeting with members of the Lincolnshire Learning Disability Coalition, carers' groups and disability networks.
- Developing dialogue with Managed Care Network partners and SHINE members (Mental Health Support Network in Lincolnshire).
- Developing communication channels with the above through press articles, e-mails, partner newsletter and telephone contact for stories of personal experience.
- Developing and delivering a short-term pre-vocational programme called Get More Confidence to offer light-touch enablement support to individuals at risk of / experiencing mental ill health.

We devised a survey called Bridging the Gap to ask people what helped and what hindered them in maintaining mental health and wellbeing, which we distributed amongst our networks of disability and carers' groups, including the Managed Care Network and we publicised this initiative in the local press.

We also consulted our own service users and staff and drew on the findings of other local research including the responses to the Lincolnshire Adults with Autism public consultation to inform the development of a joint health and social care commissioning strategy for 2013 – 2016.

We heard from adults who have experienced mental health difficulties through cuts to or loss of support and the distressing impact this is having on their mental wellbeing and others around them including family and friends. We heard from parents and carers who increasingly struggle to support their adult children as they themselves are ageing.

We also heard from adults who are benefiting from one or more of the Managed Care Network services that have been developed through the Mental Illness Prevention Fund, introduced by Lincolnshire Partnership NHS Foundation Trust and Lincolnshire County Council to help people affected by mental health problems.

We undertook this research because:

- We wanted to make transparent the mental health needs of adults with learning disabilities living in Lincolnshire, to identify not just what works and what could be better, but to identify good practice and emerging services which point the way to a

shared vision for the future, which has local services meeting local needs that implement the known good practice that already exists.

- Good practice is evident in member organisations of the Managed Care Network, who are achieving positive results using a 'social prescribing' model that could be described as 'light-touch' enablement support. Whilst these projects often struggle for funding, they can be a lifeline to individuals in helping to build friendships, social capital, work experiences, skills and confidence.
- At a time when local authority budgets are contracting, there may be an over-reliance on the voluntary and community sector to deliver mental health support services which, without consistent funding, threatens to undermine some of the gains that have arguably been made by developing local services to meet the needs of local people.
- Changes in eligibility criteria for social care support have resulted in adults with moderate learning disabilities experiencing cuts to or loss of support services, resulting in them being 'stuck at home' and experiencing social isolation, increasing the likelihood that they may experience mental health difficulties.
- People with learning disabilities still experience barriers to using health services; difficulties in communicating their needs to health service personnel; health inequalities due to biological, psychological, social and life experiences; barriers to work experiences and employment. They can also become involved in situations where their behaviours are misconstrued or inappropriately dealt with, resulting in the involvement of the emergency services and very negative impacts on individual wellbeing.
- Most importantly, we feel it is vital that everyone can exercise individual choice and control over the type of services they need – including mental health services - to live the life they want with the support that they need.

Experts through Experience

Several individuals told us how their experience of services (or lack of them) had impacted on their mental health and wellbeing.

Pulling her hair out

One young lady whose story we discovered had been subject to an Ordinary Residence process for Lincolnshire to assess and take on funding for.

The assessment was undertaken and the outcome was that she would not receive funding for her employment services and she would also have a reduction in support hours. It took some time for her to stop attending her employment services after many attempts by staff to try to discuss and explain the outcome of the assessment.

She did stop attending, but displayed distressing behaviours including pulling her hair out, not taking care of herself, over sleeping and not engaging with support. Her obsessive behaviours also increased.

Medical advice was sought in regard to her behaviour / symptoms and response to no longer attending employment services. Her GP actioned a written response to evidence that this was directly linked to her current situation and lack of stimulation and activity.

One person in a service can make a big difference – a father's story

'Due to a sudden change in economic conditions where my son worked, they had to make most workers redundant. My son was lucky to be assigned to a dedicated adviser at the Job Centre. The adviser was of great help in finding courses and they were of some benefit, but like most people, my son wanted a job. On a regular basis, my son delivered his CV to a number of firms in person, with me doing the driving.

After 13 months, the Job Centre adviser found some work experience for 3 months at a national DIY company, whilst still being paid his Job Seeker's allowance. This was a great boost for him. This was a good experience and 6 months later, resulted in a 2-month contract on the minimum rate with the same firm. Even today, the staff at the firm will come up for a chat if they see him in store. Being unemployed is not an easy life. As a family, we called on his help whenever we could and also maintained a social life by going out together.

After February 2011, we continued to deliver CVs to as many firms as we could, but this time, with the approval of the Job Centre adviser, we attached a letter to the CV, giving the phone number of the Job Centre adviser as the first point of contact. Most employers are sympathetic and will confirm that they will keep your details on file, just in case they have a vacancy. In April 2013, a company contacted the Job centre and offered work on a month by month contract.

My son started on this basis and in September 2013 was offered a permanent position from 1st October.'

How lonely and isolating Autism can be...

'There are all of these services and initiatives out there, but because Tom* is so reclusive, he won't go.'

Tom (18) who has a dual diagnosis of Autism and Pathological Demand Avoidance has excelled academically in a mainstream independent secondary school after receiving 'fantastic' support from a local authority home tutor and the benefit of being in an inclusive school setting with support from the SEN department.

However, in May 2013, Tom had a breakdown and became suicidal. He went to his GP who referred him to the CAMHS (Child and Adolescent Health Services) team, who tried to be supportive. However, due to Tom's age (he was 17 at the time), he was referred onto the Archway Centre in Lincoln (Adult Mental Health Services) where he was refused support. They said that their methods did not work for people with Autism. Tom went back to his GP, but the GP was unable to offer any further suggestions. Tom's mum resigned from her job to support him fully at home. Unable to see a future and feeling like a burden, it was only with the support of his family that Tom worked through this dark spell.

At this time, Tom's family also sought an adult social care assessment, but were bounced between children and adult services due to Tom's age. His mum wrote an official letter of complaint and was issued an apology for this treatment. Tom then had an adult services assessment and was told that he would get funding for a 1.1 assistant. However, at the time of writing, this funding was yet to materialise.

Tom's mum also had a carer's assessment and obtained some funding for a short break with her husband as respite. Tom's grandparents are able to look after him in the absence of his parents. Tom's mum says that the main problem is lack of consistency between statutory services, as other people with Autism report that they do access support from the Archway Centre.

A positive turning point came for Tom when he was offered ongoing involvement in a local community film company project which has led to the offer of a possible apprenticeship in the future. Although he still suffers highs and lows, he is now able to see a light at the end of the tunnel. Tom's mum has seen a real change in him and talks about how his confidence has increased.

Tom's family are doing all they can to support him to gain independence and take up any opportunities as they arise. They are building an annexe to support him into a more independent living environment and he is involved in every step of the process, helping with planning and picking furniture. He is also interested in radio and film and has a great broadcast-quality microphone voice.

Tom's mum sums up the key challenges they face as a family: There are all these services and initiatives out there, but because Tom is so reclusive, he just won't go. She would like him to be able to access professional support to talk about his anxieties and consequential depression that Autism and isolation evoke, just as someone without Autism would have in this situation.

*Name changed to protect identity.

It only takes a wrong decision....to undo a lifetime of help and support

'Our autistic son had a very bad experience during his transition from educational services to adult social care. We did a lot of research ourselves into suitable placements; a process that we started 18 months before he was due to change from an educational residential to an adult placement. He wanted to carry on living out of county and his current placement said he would benefit from another 2 years in an educational setting. He was 22 at this time but was refused any further educational funding. Doctors and a psychologist both said he would benefit from staying in his current placement but this was ignored by social services. He had assessments at adult places he wished to go onto but they all said he was not independent enough and needed to stay in his current college placement for longer. This was refused even when we offered to pay for the education part of funding ourselves. When he finished at college, he returned home for a year due to this. I had to give up a job I had loved and done for the past 15 years.

The whole process caused him to become anxious and refuse to go out – loss of mobility due to fear. He would not even go from room to room without holding onto someone. Also, he started to wet himself as he was so frightened of walking. He used to get up and go to the toilet when he needed. Now we need to ask him if he needs to go and take him. This is very upsetting when he has been clean since he was small.

He was put on medication for his anxiety but this only helped a little. Before this, he was a very sporty, outdoor person who had never taken any medication before as everything was managed by his environment and support. Still, 15 months from leaving college, we are only making small steps. He is now in a residential placement where they are working hard to help him. This is in-county. We have been told it will be a long process to get back the happy confident young man that he once was.

The effects of people not listening to what he needs have caused us to lose a very happy young man, who had built up confidence and some independence over the years. A lot of people had helped in this process. It only takes a wrong decision – refusal to fund education and out-of-county placements to undo a lifetime of help and support.'

A struggle to get involved

A carer told us of a young woman who had been through the Ordinary Residency process and was now under Lincolnshire as her funding authority.

'Prior to the changes she was receiving three days' employment services, where she was able to engage with others and participate in appropriate activities for health issues.

When the assessment was completed, she lost the funding for this as the funding was not being continued for this aspect of her support. Also, this came at a time when the Supporting People funds were being transferred to the Housing Related support and her hours were reduced for this also as the maximum providers were able to claim for this was 8 hours per week. Prior to this, she had been in receipt of 24 hours care per week. She had been assessed as not requiring Adult Social Care funding, so we were left with a specific criteria that did not include on-going medication and health requirements. We were able to request a re-assessment and received a further 7 hours per week to cover these needs.

During this period of change, we did see her diabetes become unstable as we were supporting her for less hours to supervise menu, food intake and shopping. She cannot financially afford to purchase these services from her own budget and with the reduced support, she does struggle to become involved in appropriate and meaningful activities.'

I feel like everything is taking huge chunks out of me at the moment and I can't escape

'I don't like being at the bottom of the ladder. I have a degree. If I was able to find the right niche and was working with people who understood me, I'd be fine. It's increasingly hard to find that, in a world entirely driven by how lean it can be and how much money an organisation can make....I feel like everything is taking chunks out of me at the moment and I can't escape.'

It felt like a wild goose chase

A 19-year-old woman, who had been diagnosed with Asperger's at the age of 15 and was struggling to access higher education opportunities because of her mental health, told us how a specialist told her to socialise, get out more and pick herself up.

She told us: 'I was supposed to see one specialist originally but saw someone else instead. She asked me a bunch of things about my past. I told her I had a diagnosis of Asperger's and how I found it interplayed with stress and made me feel low. Five minutes later, the doctor said that I was not autistic and not depressed. She referred me back to my GP and said the best thing to do was to be happier and get exercise etc.'

'It felt like a wild goose chase because I had been pushing to get a referral to Sheffield hospital for re-assessment of my diagnosis and my health in general. It felt like a dead end.'

Postscript: After making a complaint, this young lady was able to access the re-assessment she wanted.

A mother's story

The mother of a 24-year-old woman with Autism / Asperger's Syndrome told us her daughter's life story describing the vicissitudes of life punctuated by the many services she had endeavoured to access and secured, with widely differing results.

'At the beginning of 2009, through Share the Care (which no longer exists – it is now Carers Connect), my daughter had an assessment for benefits and we were able to get her onto DLA (unfortunately, the lowest rate for care and mobility) and income related ESA (Employment and Support Allowance). As part of the condition of going on ESA, she had to go and see the Pathways to Work lady, who was very good with her.

During this time, the National Autistic Society suggested my daughter write to Lincolnshire County Council and ask for an assessment under Section 47 of the NHS and Community Care Act.

In 2009, she was assessed by the learning disability team at Grantham and then referred to Beaconfield Mental Health Unit at Grantham. Unfortunately the person in charge of my daughter's care would not listen to what she wanted to do and told her she had to change for the world she lived in, in about 6 weeks. After a lot of tears, my daughter had a meltdown and we couldn't get her out of the house for three months.

I had to explain to the Pathways to Work lady what had happened and gradually I got my daughter out of the house again. We were informed that there were no jobs suitable for our daughter's requirements at that time.

Then we were told by the Pathways to Work lady that the Government was changing everything and my daughter had to go back to the learning disability person at the Job Centre. This was very distressing for my daughter as she had started to relax and talk to this lady. When she first went to see this lady, she sat there in her coat and sunglasses and wouldn't say anything. Gradually, over the space of approximately 2 years, she started to relax and talk to this lady about what programmes she watched, what DVDs she watched and what music she liked listening to.

The disability employment lady at the Job Centre told us that there no jobs suitable for my daughter and the lady suggested we appeal to be transferred to the support group of the ESA which we did and won. The people at the tribunal (December 2011) listened to my daughter and how she felt and asked us how it affected her, because she cried and ran out of the room. My husband had to go after her because of one of the questions she was asked.'

'Bridging the Gap' survey

We carried out a survey of adults with learning disabilities in Lincolnshire over a period of approximately 6 months, which also enabled families / carers to express their views. We received approximately 40 responses to the survey from individuals and a further 20 responses from families / carers. We called the survey 'Bridging the Gap,' because of the experience of several service users known to Linkage who felt that they had fallen into a 'gap' between services after they had experienced cuts to or loss of services.

We also invited responses to the questions listed below from some of our partners in the Managed Care Provider Network, including New Life Church, Spilsby, who operate a range of social activities and support services for and including adults with learning disabilities and / or mental health needs and also Lincs Floating Support, a tenancy support organisation offering housing support to young people aged 16 – 25.

Questions specifically included the following:

- **What is good for your mental health and wellbeing?** (or that of the person you support / care for).
- **What is bad for your mental health and wellbeing?** (or that of the person you support / care for).
- **What would help you** (the person you support) **to feel better / have good mental health and wellbeing?**
- **Have you tried this help? If you have, how was it?**
- **How is your mental health being affected or at risk of being affected?**
- **If you are a carer, how is this affecting the person you care for? Tell us your story.**

What is good for your mental health and wellbeing?

The vast majority of responses were focused on access to meaningful activities, healthy lifestyles, social, leisure and recreation options and opportunities, including access to computers and mobile applications for leisure and work, work / volunteering opportunities, being listened to, time to relax and express feelings and services which were responsive to need.

Or that of the person you care for?

These responses mirrored the above but additionally covered wider issues around routines and support.

'Allowing him to feel and be busy. Giving him jobs to do. Having friends around him. Praise.'

'Structure, familiarity, Family contact and visits. Feeling safe. Able to access leisure and a regular work routine. Being listened to. Having a regular key worker who she trusts and can go to.'

Being warm, cosy and having suitable and fashionable clothing for winter. Having regular haircuts and style. Also regular beauty treatments. Being as independent as possible and moving towards more independence within the parameters of vulnerability.'

'Having access to his computer to de-stress.'

What is bad for your mental health and wellbeing?

The responses here focused on 'lack of' or not being able to do something, including the activities mentioned above.

'Not being able to go out to the pub with my friends. Not being able to go to work. Not being able to go to the gym. Not being able to go shopping or buy presents for my family. Not being able to go to car boot sales. Not being listened to....'

'Being alone. Not being able to get out to work or on leisure.'

'Not having my own space, being in crowded places.'

'Not being able to use my computer.'

Or the person you support / care for?

Again, these responses mirrored the above.

'Being bored. Being stuck in the house and not being able to get out doing activities every day.'

'Change. Feeling unsafe. Being unable to access leisure and a work routine. Not being listened to or understood; not having a voice. Health issues going undiagnosed or untreated. Being cold. Not being able to talk to and visit family. Being bullied.'

'Staying on his own for long periods of time. Being restricted.'

What would help you (or the person you support / care for) to have good mental health and wellbeing?

Many responses here repeated aspects of the first question **What is good for your mental health and wellbeing?** but additionally included aspirational factors.

'To continue to get support, to have access to better services linked to mental health and learning disabilities, lifetime support, help with family issues. For others to have better understanding of both mental health and learning disabilities.'

'To carry on living independently in my bungalow. Seeing my friends and boyfriend. Going to work. Ensuring I carry on taking my medication and keeping well. Being supported by Linkage.'

'Access to some form of informal support.'

'Services designed for me and my peers e.g. sporting activities, social events etc.

Families / carers answering this question also made specific responses including: robust support plans, person-centred planning, structure and familiarity, plenty to do, aromatherapy and other complementary therapies; use of Makaton to help with communication and regular trips out.

Have you tried this help? If you have, how was it?

Responses to this question were generally positive, though some individuals felt the lack of enough support hours was unhelpful.

'I get support but only certain set hours.'

'Activities – going out and seeing friends makes me happy. Work – look forward to starting a new work placement. Greater support hours – not been tried. I am currently only funded for 8 hours a week which I find wrong. I miss sometimes going out with the staff. I miss going out on activities and holidays.'

'Support service – this service has worked well, has supported me through some issues, but only lasts for 2 years. I attend 2 mental health groups and this allows me to mix with others and have contact outside my family – without this I would feel isolated.'

How is your mental health being affected or at risk of being affected? If you are a carer, why is the mental health of the person you care for being affected?

Some individuals spoke about how their mental health had already been adversely affected – others spoke of their anxiety about potential / future loss of services / support.

'I feel if I did not work or have the opportunity to see my friends, I think I would become closed off and become aggressive and I believe this would make me unwell.'

'Because of my autism, I can be easily stressed and too much stress could make me feel ill and mentally fragile. Too much stress could cause depression, self-harm and seclusion.'

'If my hours get cut, I will struggle to cook, clean, pay bills. When my hours were cut, I was found wandering round all day and doing things I would not normally do. I was in a bit of trouble.'

'My mental health is not at all at risk where I live as I am kept busy both with leisure and day services. I have lots of friends where I live and socialise regularly.'

'It is affected as I like a routine in my life and if the level of care is reduced, this impacts on my life as I need lots of motivation to do the simplest of tasks. If I am left on my own, I will watch TV 24

hours a day, not wash or do chores and at times, not eat. I may dress in the wrong clothes and draw attention to myself at times, negative attention.'

Carers answering this question included the following in their responses:

'I believe that independence is a massive part of ensuring our residents' wellbeing and mental health. Achievement makes people feel good about themselves. If they aren't achieving or feel they aren't, people can become withdrawn and isolated and this may eventually lead to depression and more serious mental health problems.'

'He has very limited knowledge of his mental health and can be greatly affected by changes around him, from small everyday situations he encounters, such as staffing changes, timetable interruptions, mood on the day. He is also greatly affected by funding arrangements for his placement here as a college learner and will be in the same position once a longer-term placement post college is being sought.'

'I am completing this questionnaire with relevance to the Linkage residents I work with as a whole rather than as an individual. I feel it is important for our residents to be a part of the local community. Whilst many Linkage staff strive to achieve this, I find it is often a lack of understanding and knowledge of others living in that community that causes a problem.'

'For example, a young man with autism who attends sector college at Boston independently went through a period of being bullied on the college bus. This stopped eventually, as the other young people got to know and accept him and his differences, however, I believe this happened due to a lack of understanding on their part.'

'Another example, which I come across regularly, is people in the local community assuming our service users cannot do things for themselves. I have often witnessed shop assistants etc. taking the service users' money from them and counting it out for them as they assume they cannot do it themselves.'

Adults with Autism – public consultation evaluation report

For the first time, a national condition-specific strategy has been developed by the Government - around the needs of adults with autism in England. 'Fulfilling and Rewarding Lives,' the Government's strategy, was published in 2010 with the key aims of:

- **helping adults with autism to access the services they need easily and free of discrimination**
- **improving diagnosis**
- **increasing awareness of autism across health, care and community services.**

It is incumbent on all local authorities to develop their local strategies to breathe life into the national strategy at local level. With this in mind, Lincolnshire County Council and NHS Lincolnshire agreed, in February 2012, to develop a Joint Health and Social Care Commissioning Strategy for Lincolnshire with the aim of improving services for adults with autism.

Linkage Community Trust is represented on the Lincolnshire Autism Partnership, which is a body of people with autism, carers, community representatives, voluntary groups and professionals set up to advise on the Adults with Autism Strategy for Lincolnshire.

As part of the implementation of the strategy, a public consultation exercise was conducted between December 2012 and March 2013, which yielded 214 questionnaire responses, the findings of which have also been used to inform some of the **Recommendations** and **Aspirations for the Future** included at the front of this report.

Whilst the 'improving health care' section of the consultation did not specifically refer to mental health services, some of the key issues which emerged reflect the Findings in this report.

Key issues included the need for:

- training for health and social care staff in relation to autism
- improved environments within healthcare buildings
- more accessible / welcoming GP surgeries with easy access to booking appointments and effective communication
- accessible information and advice regarding support available, including housing, education, employment, welfare benefits, education and support for families;
- a more effective process of getting a diagnosis with clear follow-up information, advice and support
- clear pathways of care and support
- better information about what help is available in the community if a person is not eligible for social care services
- a co-ordinated approach to transition from Children's to Adult services and other life transitions experienced by adults with autism.

Issues raised by disability networks / other support groups

The mental health needs of people with learning disabilities were discussed in several different forums, including Lincolnshire Learning Disability Coalition, with members of the Managed Care Network, including New Life Church, Spilsby, who offer a variety of social activities and services to support people with additional support needs including adults with learning disabilities and / or mental health needs and with Lincs Floating Support, a tenancy support organisation for young people aged 16 – 25.

Below is a summary of issues which emerged:

- Professionals seem to only know how to deal with either learning disabilities or mental health. If a person has both, they don't seem to fit into any service and professionals don't know how to support them.
- There is a need to recognise what support is out there in the community. Often groups don't know about each other. Groups need to be better connected and network with each other rather than operating in isolation.
- We need to take a preventative approach and try to support people before they go into crisis and develop mental health problems.
- There is not enough support across the county – some areas have plenty of support available, other areas have nothing.
- Peer support is valuable as it helps people build social networks. Longer-term attendees can support new attendees, overseen by a facilitator. Peers are able to help and support each other and build on their individual talents, helping people to help themselves.
- Linking in with community churches has been valuable for many individuals.
- Transport issues and the rural nature of the county is a problem – it makes accessing groups and services very difficult. It also increases the likelihood of people being isolated and stuck at home with nothing to do.
- Volunteering / work experience has many benefits including offering social interaction, empowerment and improved confidence.
- It is important that support services and groups offer people a safe place to go. They are most effective if they are homely, warm, friendly and inviting.

Get More Confidence

As a response to issues highlighted by adults with learning disabilities about the lack of community-based opportunities, Linkage set up a small programme called Get More Confidence, which ran for half a day per week over a period of 11 weeks from October to December 2013.

The idea was to develop a 'light-touch' transitional support service available for adults with learning difficulties or disabilities whose mental health and wellbeing was being compromised by lack of access to support services which addressed their needs.

What developed was a small group-based activity with other individuals accessing advice, information and guidance on an ad hoc basis.

A total of 5 beneficiaries accessed support through this route, with two members participating every week through the entire programme and a further member coming along half way through the programme and staying on until it finished. Staff from Bishop Grossteste expressed support for the service and offered us access to their Curiositea café / tearoom on their Lincoln campus. The small group programme was delivered at Linkage's Lincoln office by two members of staff and concentrated on the following:

- Exploring an individual's confidence in different areas of life
- Skills and strengths
- Perceptions
- Values, skills and interests
- Exploring different types of work activity
- Goal setting and action planning
- Making changes happen
- Managing stress
- Communicating more confidently
- CV preparation

In addition to these core elements, we explored skills through craft making activities (including making leaded glass mirrors / vases), outings and visits.

Beneficiaries

- 1 young man (19) accessed help and support to find a part-time job whilst studying at college in Lincoln.
- 1 young man (18) who visited us is now volunteering with Linkage.
- 1 young lady (29), who is physically challenged, attended the entire programme and is now volunteering with Linkage as a member of the Business Development team as an administrative assistant and undergoing training as an Easy Read ambassador.

- 1 young lady (30), who experiences mental health difficulties, started attending part-way through the course and managed to attend each week subsequently.
- 1 man (41) who also accessed the service every week, was also supported in his workplace review in his volunteering job at a local hospital.

We developed a set of Get More Confidence materials along with a flyer and we distributed the materials to other members of the Managed Care Provider Network.

Evaluation / comments about Get More Confidence

'This is the only thing I have been aware of which might help me.'

'There is a value in being with people – not being cut off.'

'It's good to have a friendly supportive environment.'

'It's useful to have something to leave the house for if you have issues about leaving the house.'

'I didn't have a purpose beforehand.'

'Social interaction is good, particularly for people who might not otherwise see anyone at all.'

'People with autistic spectrum conditions are very scared of being around people who don't understand them.'

'Some services finish with you early. I went to.....and they finished with me. Then I never heard from then again. Having a service where you can stay in touch is good. I think there's definitely a gap (in services) there.'

'Some projects are set up and they are good while they last, but then they are not there anymore.'

'There's a need for a service that is regularly available where the people who are running it are not going to cancel on you or finish with you.'

'It's social support that's needed for some people, not clinical support.'

'This sort of course is good for people who want to help themselves and are prepared to come more than once.'

Literature Review

A health needs assessment for adults with a learning disability in Lincolnshire⁴

This report recognises that people with learning disabilities are at greater risk of developing mental health and behavioural disorders compared to the general population and reveals that children and adults with severe or profound learning disabilities, experience greater mental illness compared to those with mild or no learning disabilities.

'Evidence suggests that the rate of anxiety and depression may be higher in adults with a learning disability resident in the community, compared to those who are institutionalised, which may be explained by the added stress of managing daily life, particularly if support is limited and there is insufficient consideration of lifestyle issues.'

In addition to the data introduced in the Foreword, the report indicates that local clinical data from primary care records in Lincolnshire show twice as many adults with learning disabilities have dementia compared to all patients registered with a GP (1.4% vs 0.7%). Deaths from dementia are more common in men than women with moderate to profound learning disabilities, although the prevalence of dementia is more frequently diagnosed in women.

The report also includes potential vulnerability factors for developing mental ill health in people with learning disabilities. Most of these factors are external variables which include:

- attitudes, expectations and values
- support and relationships
- inappropriate environments and services
- under or over stimulation
- stigmatised role or role model
- financial and legal disadvantage
- deprivation or abuse
- separation or loss / bereavement / 'letting go'
- positive or negative learning experience
- self-esteem or insight
- diagnostic issues
- lifecycle transitions or other crises
- social or community networks
- stress
- adaption to disabilities
- relationships

⁴ A health needs assessment for adults with a learning disability in Lincolnshire, NHS Lincolnshire, 2012

The report also says that: *'difficulties are apparent in accessing mental health care because carers and entry-level professionals sometimes interpret symptoms and signs of mental ill-health as an aspect of the person's learning disability (overshadowing).'*

Furthermore, *'access difficulties are exacerbated by confusion over the relative roles and responsibilities of mental health services, as opposed to learning disability health services.'*

The other care crisis: Making social care funding work for disabled adults in England⁵

This report highlights the increased risk that learning disabled people have of developing mental ill-health but also the importance of providing low-level support in order to prevent needs from escalating and reducing the risk of onset of mental illness.

It reveals that because *'disabled people are failing to be supported to wash, dress, leave the house and communicate with those around them, they are withdrawing from society, becoming reliant on friends and family to provide care and support, often driving those relationships to crisis point... This has meant that levels of stress, anxiety and mental health conditions are rising as a result.'*

The report says that 'nearly half of disabled adults report that services aren't supporting them to get out into the community' and one-fifth of people with learning disabilities surveyed by the Learning Disability Coalition in 2011 were told that their hours of care would be reduced.

The other care crisis says that 'some people with high functioning autism or Asperger's may only need some seemingly low-level support, such as help with social skills and managing about the house (e.g. with bills and organising cleaning activities). Frequently, these types of need are not recognised by councils as being 'substantial.' Yet, without this help, this group are at risk of developing more severe problems, such as social isolation and severe mental health problems.'

The report reiterated the findings of a Scope survey (2012) which found that more than half of the respondents (53%) said that they felt anxious, isolated or experienced declining mental ill health because they had lost care and support services.

Peer support in mental health and disability⁶

This report makes a clear statement about the value of peer support:

'The key messages from the Foundation's work confirm what the literature suggests – the benefits of peer support are widespread, for the individual receiving the support, the person giving it and for services. They include better mental health, an increased sense of wellbeing, increased confidence and learning skills, greater social connectedness, improved recovery and coping skills and fewer hospital admissions.'

⁵ The other care crisis: Making social care funding work for disabled adults in England, Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability, 2013

⁶ Peer support in mental health and disability, Mental Health Foundation, 2012

The Mental Health of Children and Adolescents with Learning Disabilities in Britain⁷

Although this report is focused on children and adolescents rather than adults with learning disabilities, it is helpful to explore the findings as it is possible to draw comparisons between the age groups and there are, arguably, similarities which may be applied to adults with learning disabilities.

The report found that 'over one in three children and adolescents with a learning disability in Britain (36%) have a diagnosable psychiatric disorder. Children and adolescents with learning disabilities are over six times more likely to have a diagnosable psychiatric disorder than their peers who do not have learning disabilities.'

Like *the health needs assessment for adults with a learning disability in Lincolnshire*, this report emphasises the role of external factors in the development of mental ill health amongst those with learning disabilities: 'this is consistent with the view that the increased rates of mental health problems among children and adolescents with learning disabilities in Britain is more to do with their increased exposure to poverty and social exclusion than being something inherent in having learning disabilities...children with learning disabilities are at much greater risk of having mental health problems than children who do not have learning disabilities. But they are also poor, live in less advantaged family circumstances and have fewer friends; all of which are known also to be associated with an increased risk of mental health problems.'

'When we take these factors into account, the risk apparently associated with learning disabilities is reduced by at least two-thirds... this is consistent with the view that the increased rates of mental health problems among children and adolescents is more to do with their increased exposure to poverty and social exclusion than being something inherent in having learning disabilities.'

The report also poses the view that 'the intellectual impairment associated with learning disabilities reduces the child's capacity for finding creative and adaptive solutions to life's challenges...some particular causes of intellectual disability lend vulnerability to particular types of mental health problems.'

It also revealed a lack of support for those with a learning disability and mental illness, with just under half of the families consulted reporting that they had received no helpful support from services.

⁷ The Mental Health of Children and Adolescents with Learning Disabilities in Britain, Lancaster University, 2007

Making Us Count: identifying and improving mental health support for young people with learning disabilities⁸

This report estimates that *'approximately one-third of a million people in the UK have learning disabilities. Of those, 40% are likely to develop a mental health problem...young people with learning disabilities are far more inclined to develop emotional difficulties such as depression and anxiety and these conditions often go unrecognised and untreated.'*

It reported that 'some of the most common messages the inquiry and the researchers heard were the difficulties young people faced in accessing suitable college or work placements, accessing leisure opportunities and maintaining friendships or relationships. This lack of opportunities, which other young people take for granted, were often the triggers to mental health problems.' This supports the commonly-held view that social isolation and lack of opportunities to access the community are key factors affecting the mental health of people with learning disabilities.

The report emphasises the risk of people slipping through the net and not being able to access the support they need. It says that: *'it can be particularly difficult for young people with moderate and mild learning disabilities and they too may not be seen by any service.'*

It highlights one of the key barriers to getting help with mental health issues as stigma, with people often reluctant to seek help because they feel ashamed or are afraid of being labelled and unsure of the consequences of receiving such a diagnosis. A further issue for those with learning disabilities is that mental illness may be masked by their existing difficulties. Symptoms of mental ill health may be more difficult to identify: 'family carers often did not appreciate that the changes they were seeing in their growing children were indicative of emotional distress, rather than as a result of their disability.'

To combat the issue of identification, the Mind the Gap project aimed to separate out the issue of labelling from that of recognition. The aim was not to focus simply on those with a dual diagnosis of learning disability and mental health needs, instead the project aimed to include all young people with learning disabilities who had mental health support needs, often unrecognised.

The report details the importance of *a single point of contact, improved exchange of information and co-ordinated provision* as issues that could make access to support for people easier.

Reference is also made to the value of the voluntary sector in supporting mental wellbeing, particularly the way in which voluntary organisations often adopt a holistic approach to supporting the young person and their family and carers. The report however, also cautions an over-dependency on voluntary services as they may be under-funded and under-resourced to cope with the demands placed on them.

⁸ Making Us Count: Identifying and improving mental health support for young people with learning disabilities, The Foundation for People with Learning Disabilities, 2005

Green Light Toolkit 2013⁹

The National Development Team for inclusion has launched a practical guide designed to help improve the quality of mental health services for adults with learning disabilities and adults with autism.

Commissioned by the NHS Confederation and supported by the Department of Health, the guide builds on the report *Reasonably Adjusted?*¹⁰

The Green Light Toolkit includes:

- an audit framework to support reviews
- an easy read version of the audit framework and toolkit
- a database of examples of reasonable adjustments made by services as a resource for people seeking to innovate and share training.

⁹ Green Light Toolkit 2013: A guide to auditing and improving your mental health services to be effective in supporting people with autism and people with learning disabilities, National Development Team for inclusion, 2013.

¹⁰ Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities, National Development Team for inclusion, 2012.

Appendix A: References / Further reading

The other care crisis: making social care funding work for disabled adults in England, Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability, 2013

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