



Exploration of peer support models for individuals within Learning Disability and Neuro Diverse communities relating to mental health peer support

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Introduction

NHS England's Five Year Forward View refers to peer support as one of the 'slow burn, high impact' interventions that should be seen as 'essential' to the future of the NHS. This document provides insight and guidance about the potential need for, and experience of, mental health peer support to Learning Disability and Neuro Diverse communities.

The aim is to help Health Education England in its wider consideration of peer support roles, to review how, for Learning Disability and Neuro Diverse communities, both life experience and mental health experience can be used in a positive way to support others.

These areas for consideration are informed by a desk review, and by the expert input of 20 people.

Thanks go to: 13 members of the community with lived experience, amongst whom five were autistic people, five were people with learning disabilities and two were parents of individuals from this community.

Professional input was from: Mary Busk, Co-founder of National Network of Parent Carer Forums and Family Carer Advisor, NHS England; Debbie Gadbury, Family Support Services and parent, Sycamore Trust UK; Isabelle Garnet, Parent Carer Advisor to NHS England; Becki Meakin, General Manager, Shaping Our Lives; Sarah Ormston, Health, Dementia and Wellbeing Manager, MacIntyre; Jane Salazar, Peer Support Officer, Mind, and Peer Support Group Founder and Facilitator of SM Talking Circles; Mrunal Sisodia, Co-chair, National Network of Parent Carer Forums.

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Background and context

‘Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibilities and mutual agreement of what is helpful’ (Mead, 2003)

By working alongside core mental health service staff, peer support can achieve a recovery focused, comprehensive and integrated service by providing the individual with someone who is relatable with a similar lived experience.

Over the past ten years there have been vast amounts of research demonstrating the benefits not only for an individual receiving peer support, but for the peer support worker as well. Individual services vary depending on type of provision, quality of training and supervision. However key benefits have demonstrated improvements in: problem solving skills, self-esteem, confidence (empowerment and hope), access to meaningful engagement such as work and education, social relationships and community cohesion (being understood and reducing stigma) (Repper *et al.*, 2013; Davidson *et al.*, 2012; Repper & Carter, 2010; Bradstreet, 2006). There is, however, little research based on peer support for people with learning disabilities. Our interviews have found the main benefit of peer support is “being able to just be. I don’t have to talk because I know they understand what is going on in my head” (Expert by Experience FPLD peer mentor).

Repper *et al.* (2013) identified the eight core principles of peer support as: mutual, reciprocal, non-directive, recovery focused, strengths-based, inclusive, progressive and safe.

The two areas of importance for this topic are: **mutual** – experiences aren’t identical but there is a shared experience and understanding of mental health; and **inclusive** – an understanding of that experience within the individual’s community. This is furthered by Faulkner and Kalathil (2012) who identified that peer support is most effective when the shared experience isn’t solely focused on the condition, but on a commonality of cultural background, religion, age, gender or personal values.

“I feel I don’t have to speak here. They know how I am feeling as they feel the same.” – Young woman with autism support group, Sycamore Trust

Therefore, what is needed for individuals from Learning Disability and Neuro Diverse communities to access mental health peer support services is a shared experience of the mental health condition and an understanding/commonality of background (which, for this community, is Learning Disability or Neuro Diversity).

Learning Disability and Neuro Diverse communities cover a wide range of individuals and needs who will view and approach the world in very different ways. They are distinct groups. The Department of Health defines a Learning Disability within its *Valuing People* white paper (2001) as a “significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood”. It is an umbrella term which covers a plethora of conditions which can be mild to moderate to severe.

Neuro Diversity is “...a concept where neurological differences are to be recognized and respected as any other human variation. These differences can include those labeled with Dyspraxia, Dyslexia, Attention Deficit Hyperactivity Disorder, Dyscalculia, Autistic Spectrum, Tourette

Syndrome, and others” (National Symposium on Neuro Diversity, 2011). In other words, these brain differences are exactly that: differences, i.e. normal variations within the brain.

The Learning Disability Observatory estimates that approximately 2% of the population in the UK have a Learning Disability and/or Neuro Diversity (930,400 adults and 156,700 children), with a higher proportion among children and young people (2.7%). The spectrum of mental health problems experienced by those with Learning Disabilities or Neuro Diversity is the same as for the wider population, but with a **higher prevalence**, with up to 40% of people with learning disabilities being at risk of developing mental illness (Taylor *et al.*, 2004; Cooper *et al.*, 2007).

- Dementia prevalence is 21.6% as opposed to 5.7% for those aged 65+ (Cooper 1997a), and individuals with Downs Syndrome are at higher risk with an onset of 30-40 years younger than the wider population (Holland *et al.*, 1998).
- Schizophrenia is nearly three times more likely (3% vs 1%) (Doody *et al.*, 1998).
- Anxiety and depression rates are unclear as it is thought that these conditions are poorly identified and treated; however Stavrakaki (1999) demonstrated prevalence rates are similar to the wider population. Collacott *et al.* (1998) highlighted that rates are higher for those with Downs Syndrome and it is the most prevalent co-morbid condition with ADHD (Heidi *et al.*, 2019).
- Autistic people are more likely to have co-morbid mental health condition and increased suicide ideation (The Lancet, 2016). Heidi *et al.* (2019) identified that 72% of children with ASD had at least one co-morbid diagnosable psychiatric condition. This is an extremely high-risk group and it is thought that 1 in 7 children and young people with a learning disability and/or neuro diversity will have a mental health need.

Feedback from our interviews highlights that this group often feels ignored until they reach crisis point, when their behaviour is described as challenging and are more likely to be admitted to hospital.

Despite this higher prevalence, people from Learning Disability and Neuro Diverse communities are less likely to access a mental health service due to lack of partnership working and communication between mental health and Learning Disability services (Hassiotis *et al.*, 2000; Moss *et al.*, 1996; & Roy *et al.*, 1997). Further barriers include long waiting times and diagnostic overshadowing, where the individual’s Learning Disability status remains the primary focus despite the mental health need resulting in people feeling isolated and unsupported. This, along with stigma or a belief that people from these communities cannot experience the same feelings as the rest of the population or benefit from good support, places them at further risk (Burke, 2014).

“I am worried you are not taking me seriously because I have a Learning Disability” – Feedback from an individual with a Learning Disability from Ask Listen Do

“There is no point me telling anybody how I feel – they’ll do nothing” – College student with a Learning Disability

“I told them I was sad because of being bullied and they said ‘did they say sorry? So all ok then’” – Expert by Experience with a learning disability FPLD hate crime project

People often fall in gaps, unable to access mainstream services. For instance, one parent was told: “your child might be autistic so their depression isn’t treatable” (Bishop’s Stortford Independent, 2020). Access to psychological services is crucial. It is not unusual to find exclusion clauses in certain services, such as IQ thresholds. The Foundation for People with Learning Disabilities undertook research and action learning with Improving Access to Psychological Therapies (IAPT) and Learning Disability Community Teams, resulting in guidance for mainstream staff which is applicable to all services (IAPT Learning Disability Positive Practice Guide, 2015).

Isolation can also be experienced within the education setting. This often results in developing anxiety and or depression in later life:

“If peer support was offered to this group, although this would not resolve the systemic issue, it would provide the individual the skills and understanding to prevent mental health issues arising in future” – Mrunal Sisodia, Co-chair, National Network of Parent Carer Forums

When thinking about this community, we must also consider parents and carers and their mental health needs. A common theme among this group is isolation and depression resulting from the constant challenging of their parenting ability, and being criticised as over-worriers, overprotective or unable to parent. There are approximately 620,000 adults providing care for disabled children and young people under the age of 20, with a quarter providing 100+ hours of care every week (Caring More than Most, 2017). The Co-Founder of the National Network of Parent Carer Forums (NNPCF) Mary Busk highlights three of her top five tips to other parents/carers as: proactively seek help, find a way to manage stress, and find a way to deal with the emotional side of things. All of these can be helped via peer support.

Current Peer Support Provision

The provision of peer support within these communities has been driven by need and passionate individuals and is therefore varied, innovative and unique. Provision appears to fall into the following categories which can be for individuals, parents/carers or even staff:

- Peer mentors: Actively supporting self-management skills, as developed by the Foundation for People with Learning Disabilities via its side-by-side workshops using the co-produced Feeling Down Guide-looking after my mental health, providing a focus for goal setting (Burke, 2014)
- Peer mentoring/support led by people with learning disabilities and autistic people for peers by the Foundation for People with Learning Disabilities *Pass It On – Good Mental Health For All 2020* programme
- Peer led support groups facilitated by a volunteer or paid staff
- Non peer support group: a paid facilitator supports peers to support each other
- Befriending or buddying: a volunteer peer support friendship. We interviewed an Expert by Experience who invites people living locally with a Learning Disability to the pub. This has led to many people who would have been lonely and isolated to meet and make friends.

- Circles of support: bringing together families and people with learning disabilities to primarily plan ahead or generate friendship.

There are few paid peer mentors with a Learning Disability, but several examples of parents/carers.

Below are some specific examples of formalised peer support which are of particular note:

- Peer support is offered via helplines like those offered by the Carers Centre, Challenging Behaviour Foundation, Sycamore Trust and others, and are all supported by parents. This is much appreciated by callers as they feel immediately that the listener understands them and is on their side.

“Do you know, this wonderful mum answered the phone and she got it; she knew what I was talking about. She did not see me as a difficult parent and knew what my daughter’s needs were. She also came with me to my meeting with social services. That I really appreciated as I felt not alone”
– Parent.

- Expert citizen checkers who are employed by housing providers to check quality and satisfaction of support and housing offered to peers. A model well used but not well evaluated.
- CQC peer experts who are employed and trained to undertake visits and inspections on commissioned services.

Mind the Gap

Between 2002 and 2004, Somerset in collaboration with the Noah Fry Research Centre Bristol undertook grass roots action research which they called *Mind the Gap*. They sought to coproduce solutions for mental health support for young people with a learning disability or neuro diversity. They developed two programmes, the first of which was called ‘The Strongest Link’, a peer support course facilitated by young people. The participants were self-selecting, all able to verbally communicate but with a varying range of needs. The training and course was undertaken for and by young people and covered friendships, feelings, growing up with relationships, getting support (health professionals in attendance), and helping yourself for example in managing stress. The six participants found improved confidence, ability to talk about their feelings, friendship, teamwork, socialisation and self-advocacy. To enable this, they found that a moderator was required to provide light touch guidance and support when things didn’t go to plan. The second programme was ‘Our Link to the Future’, a peer support group for emotional support for parents/carers. It aimed to help parents reach their own goals, rather than just being focused on the needs of their children. The attendance of the seven participants was variable due to sickness and childcare needs. Nevertheless, they experienced emotional release and developed increased confidence, assertiveness, and coping strategies.

Early Positive Approaches to Support

Early Positive Approaches to Support (EPATS), developed by the Tizard Centre, University of Kent, is a training programme coproduced with families. Parents and paid people get trained together on EPATS, a fully manualised intervention, and they support groups of families free of charge. A full evaluation is being undertaken alongside Warwick University which will inform practice.

(Learn more: <http://www.leedsmencap.org.uk/latest-news/out-trail-of-epats>)

The PEP programme

The PEP programme, run by the Mental Health Foundation, adapted materials with the Foundation for People with Learning Disabilities. The PEP programme trains teachers on a manualised mental health awareness programme. Year 11 students were trained to deliver workshops on wellbeing to year 7s within a mainstream school and a special educational needs school. Although the evaluation was not robust, the anecdotal benefits were that young people from mainstream school learned patience, compassion and how to support people who needed time to understand. The young people with learning disabilities felt extremely positive to be going to the mainstream school. Their behaviour changed; they were more confident, they felt they belonged and felt important. There were also benefits identified across the schools with individuals from the mainstream school volunteering at sports day at the special educational needs school.

'It was an extremely positive experience and something which we hope to continue further our relationship with the special school.' Deputy Head, Ilford County High

'The kids are so excited, this experience has had such an impact on them' Teacher, Little Heath School

The Sycamore Trust

The Sycamore Trust provides specific support groups for autistic girls. The training is delivered by experts by experience and the groups are either for girls and or girls and boys with a mixed age range.

"What we find is that because people have been through the same experiences in life because of autism or being a parent... this has a positive impact in terms of relationships that are helpful" – Parent and Manager at Sycamore Trust.

They also have trained autism ambassadors whose training enables them to provide peer support.

(Learn more: <http://www.sycamoretrust.org.uk/>)

Benefits

“...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.”

Mental Health Foundation, 2012

The Foundation for People with Learning Disabilities identified in their *What About Us?* action research (2005-8) that young people wanted support from peers. However, the research around Learning Disability and Neuro Diverse communities accessing peer support mental health services is less commonplace and often concludes that further research is required. We can, of course, learn from mainstream research and expect equivalent results for this group if reasonable adjustments are made. In terms of impact on service utilisation, peer support for mental health service users has demonstrated a reduction in readmissions for outpatients by 50% (Chinman *et al.*, 2001), a reduction in workload for staff (Repper and Carter 2010 p11), and a reduction in service utilisation, support from friends and family and peer support itself (Billsborough *et al.*, 2017), although cause and effect of these studies are difficult to isolate.

For this particular community, what exists is a lot of positive observations from autistic people and people with learning disabilities, as well as from parents, who clearly benefit from being peer mentors/supporters or mentored themselves, individually or in groups.

Saxena *et al.* (2019) undertook a review of 11 research articles covering online peer support (five on structured peer mentorship and six on online support groups). The research covered young people between 10-19 years old with ASD, cerebral palsy, spina bifida, ADHD and other Neuro Diversity, and care givers. The peers were individuals with a disability, caregivers of individuals with disabilities, and a virtual peer actor. They found improved social engagement and participation in life.

Kaehne & Beyer (2013) found that exposing non-disabled peers to young people within this community to support employment aided inclusion and development of non-disabled friendship networks (not mental health).

Pass It On – Good Mental Health For All

The new *Pass It On – Good Mental Health For All* programme by the Foundation for People with Learning Disabilities is being thoroughly evaluated, and the results will be available in 2021. The preliminary evidence suggests great benefits in terms of self-esteem for all: teachers, mentors and mentored (all with a learning disability or autism). Confidence is gained in terms of understanding what mental health is, and being able to think of ways to keep healthy. What we cannot make conclusions about at this stage is the overall role of mentor and what is needed to make it work.

With regards to peer support for parents/carers, most evidence is based on American or Canadian studies. These studies include literature reviews and interviews based on parents of children with medical conditions (Mirza *et al.*, 2018, DeHoff *et al.*, 2016, Schippke *et al.*, 2017). They found that

parents gained support and felt more able to advocate for their children. Our interviews reflected this, as parents stressed the positive impact on their emotional health and knowledge via peer support, whether it was paid or unpaid, particularly at diagnosis, when parents' emotions are tested.

“Speaking to another mum makes all the difference. They know what you are going through.

They offer the best advice from personal experience.” – Parent

From observation of work of by Parents for Inclusion and their ‘welcome’ pack for new parents, positive communication from parent to parent during diagnosis greatly improved attachment and ability to support their child. The message is received with positivity and hope, rather than “sorry your child is...”. However, Mirza *et al.*, 2018 indicated that there was no evidence to suggest improved self-efficacy, confidence and perceived social support or reduced depression. There was improvement in parents' coping and using social and community support and services. Their recommendation was for a consistent approach or training for parents that focuses on self-efficacy, confidence and empowerment.

Our interviews suggest the value of self-efficacy and resilience when supported by parents.

“I wish I contacted the support line sooner and meeting parents who knew what I had to do based on experience.” – Parent

“I couldn't have coped without the support from another parent. I didn't have to tell them anything; they knew what I was experiencing.” – Parent

This is in line with the outcomes from ‘Parent in Partnership’ training that supports parents to consider the social model of disability and why things are as they are. This is a model the Foundation for People with Learning Disabilities used in their Learning4Leadership programme for people with learning disabilities which supported them to not only focus on systemic stigma but their role as leaders and representing peers with a Learning Disability.

“It's important to be remembered in meeting for what is right for people with learning

disabilities, and not by just being there and highlighting jargon.” – Expert by Experience, FPLD

There are two main papers from the UK from the University of Exeter which focus on the parents of disabled children. Creating an understanding of shared experience impacts on parents' confidence and self-efficacy, which as a result helps to evaluate the services that offer peer support (Shilling *et al.*, 2013 & 2015).

Warwick University worked with the Foundation for People with Learning Disabilities to develop a model of peer support offered by parents to other parents undertaking mindfulness training. This was a randomised controlled study where some parents received mentoring and others did not (paper to be published soon). Along with the *Early Positive Approaches to Support* (EPATS) programme and its evaluation, and the FPLD *Pass it On* mentoring programme, this research will provide a lot of the answers and shine a light on the efficacy of peer mentoring programmes for both parents and experts by experience with learning disabilities and autism (Flynn *et al.*, 2020).

Challenges and barriers

Accessibility and technology: To enable access to peers who are mutual and inclusive, online forums may be the best option. However, Eysenback *et al.* (2004) highlighted that there is no robust evidence of health benefits of virtual communities, although Saxena *et al.* (2019) found that online communities *can* be beneficial. Furthermore, being supported online removes the element of local support, which during our interviews has been identified as a critical element, as your peer understands your local health and social care system. And as many people with learning disabilities do not access the internet, it is not possible to know its applicability with this group of people. People have to have access (computers and internet) and knowledge as to how to use online forums. Forums need to be moderated to address misinformation. And topics have to remain neutral, as some points of discussion can be divisive and lead to further isolation and even victimisation of individuals.

Applicability: The Mental Health Foundation (2012) found that peer support is not for everyone and people need a choice about the type of peer support they receive (Billsborough *et al.*, 2017).

Grass roots vs formalised: Some have challenged the formalising of these roles for removing the spontaneity of peer support (Mental Health Foundation, 2012). This ‘professionalising’ is deemed as over controlling-and removing the heart of what peer support is attempting to achieve (Faulkner & Kalathil, 2012). Yet without formalising these roles, there will continue to be a postcode lottery in what peer support is available.

Isolation: Accessing these communities can be extremely difficult due to many members being isolated and facing communication difficulties.

Language: The use of language needs to be considered in terms of accessibility and stigma. The Strongest Link programme discovered the use of ‘mental health’ was a barrier for access. A revised term, such as self-help, may be more appropriate. Furthermore, not everyone is aware of what peer support is; some education may be required around this or an alternative term devised such as ‘buddy’.

Meaningful involvement: For peer support to be most successful it should be designed by those who require it. Can a national model be developed which is fit for purpose whilst ensuring it is entirely user led?

Mutuality and inclusivity: These two concepts are key to effective peer support. How feasible is it to match individuals within a locality based on their mental health need and Learning Disability or Neuro Diversity, and will this not further exclude individuals from mainstream services? For instance, how appropriate is it to match someone with Downs Syndrome to someone with Autism, as their experiences are extremely different? If we are to consider, age, gender, and ethnic background, this could be very challenging. Moreover, if a peer support group is developed, it is difficult to widen the scope of that group without losing its key audience.

Reasonable adjustments: The Equality Act 2010 includes a duty to make reasonable adjustments for disabled people. These will vary considerably depending on the community and the individual but are crucial for a positive peer experience.

Support: *Mind the Gap* noted that senior management and commissioner support is pivotal to project success (Clegg and McNulty, 2002 and Whittaker, 1997). In addition to this, our interviews

highlighted that if people with lived experience are to be trained to be a ‘buddy’ they will need training and supervision to support them with their own needs and ensure that any issues around triggers are resolved.

Time: For true peer support and empowerment, people need to be supported to create and be in control of their service, and therefore more time is required. For instance, the SM Talking Circles group implemented an anonymous voting system. This takes considerably more time than setting a schedule but it enables the individuals to be in control of decision making, which is highly valued.

Workforce implications

As highlighted above, the following are crucial for the development of a peer support service for these communities:

- **Coproduction:** develop the peer support service with people with lived experience – ‘nothing about me without me’ – to ensure that it is meeting people’s needs locally and not over-professionalised
- **Engagement:** develop the peer support service with commissioners and service providers
- Work with **existing networks:** there is a wealth of knowledge and skills within the community which should be harnessed and rewarded
- Create **national standards** to ensure high quality and consistency, and to reduce postcode variations
- Create **structured interventions:** these have been found to be more effective (Saxena *et al.*, 2019) by focusing on self-efficacy, confidence and empowerment (Mirza *et al.*, 2018)
- **Train peers** to understand that sharing their own experiences is not sufficient: they need to be able to support people to be able to seek their own solutions (Faulkner and Kalathil, 2012) and ensure they are embedded within mainstream teams
- Ensure the peer has **accurate information**
- Provide **supervision** for peers to ensure they are supported in case any peer interventions impact on their health and wellbeing
- To enable the peer support to be mutual and inclusive, there needs to be a **diverse workforce** which is accessible and able to communicate in the appropriate way with reasonable adjustments
- If developing an online platform, employ a **moderator** (Saxena, 2019). This individual will not only manage content and misinformation, but be a safeguarding lead to ensure safeguarding issues and support needs are picked up and acted upon
- If developing peer groups, employ a **facilitator** but ensure that the groups are developed and run by those seeking support
- Utilise **technology** to overcome communication barriers: a budget will be required to enable access
- **Safeguarding** will be paramount in all cases.

A possible option would be to develop a national network of peer support workers. This network could be accessed by anyone seeking support for a mental health need. Peers could be filtered by age, gender, cultural background, condition and experience so someone can be supported by a 'true' peer via online platforms. This undoubtedly would require information governance solutions and access to technology for both parties, but would open up a resource far more flexible and accessible. This is the aim of the FPLD *Pass It On* mental health peer mentoring project: to develop an accredited programme of training and have a network of paid peer mentors who can be supported to deliver peer mentoring/support groups.

This would not need to restrict face-to-face peer support. If an individual wants to be seen locally, there is no reason that they cannot be seen by peer support workers within mental health services. This could be further supported by providing these workers with training around Learning Disabilities and Neuro Diversity. This would be the most cost efficient and flexible option.

Conclusions

Peer support is an effective approach which has multiple benefits for peer support workers and those receiving peer support. There is no reason that it should not be available to those from Learning Disability or Neuro Diverse communities. To be most effective, peer support needs to be responsive to intersectionality and aware of multiple inequalities. In order to achieve this, a local solution may not be feasible given the need for personalisation, notwithstanding the current financial climate of health services.

Areas for consideration:

- Undertake further research to review what is beneficial for this community.
- Separate Learning Disabilities and Neuro Diversity as they are too broad and encapsulate too many different profiles of need
- Focus on young people during transitions, as this is where there appears to be the greatest need and gap in service provision, leading to the most frustration and crisis for the whole family
- Focus on adults who are at higher risk of experiencing poor mental health and loneliness
- Ensure mainstream services are accessible
- Ensure collaboration between specialist Learning Disability services and mainstream mental health services to ensure that the best practitioner is able to offer support
- Work with people from these communities to enable them to define what would work for them
- Utilise existing networks
- Develop training programme and offer to existing services
- Consider a national peer support platform.

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