Frome Medical Practice: **CASE STUDY**

How we improved Learning Disability Health Check uptake by 21% and improved personalised care for LD patients

Increase from 67% to 88% uptake

Appointment of a LD care coordinator

Trebled our registered LD carers

Patients are receiving improved and joined up personalised care that meets their needs

Staff satisfaction has improved

Background

People with a learning disability (LD) have worse physical and mental health than people without a learning disability. On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population. The life expectancy of men with a learning disability is 14 years shorter than for men in the general population (Health inequalities – Learning disability – Mencap, 2017).

We are a large single site practice and primary care network with nearly 30,000 patients. In 2020/21 we had a total of 304 patients registered with a Learning Disability. Our review showed that only 67% of these had received an annual Health Check which was below the national target of 75%.

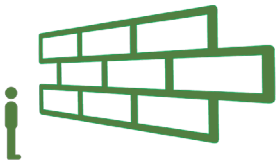
What we did

After a practice discussion we decided the support for LD Patients and improving the uptake of Health checks was best placed with our Complex Care Team. Members of the team already had the prerequisite clinical qualifications to undertake annual checks. We also had the opportunity though Primary Care Network (PCN) Additional Roles Reimbursement Funding (ARRs) to appoint a care coordinator to help improve our focus on this cohort of patients.

Our Complex Care Team specialises in supporting our most vulnerable patients. Our team focus specifically on Home Visits, Care Homes, helping to prevent unplanned admissions and discharge liaison, which helps support those leaving hospital to prevent readmission.

We then reviewed our performance against what we summarised as **9 Key Barriers to Access** based on the Learning Disability review work by Heslop et al 2014.

Results



Barrier 1 Patients not being identified as having a learning disability
Moving the care of our patients to a smaller complex care team enabled us to identify 2 patients over 12months who presented with complex health needs who had not previously been identified as having a learning disability

Barrier 2 Staff having little understanding about learning disability
While all our clinical staff had adequate training, we found having a smaller team focusing on these patients improved communication and understanding of the specific needs of patients and carers. The addition to the team of a LD specific care coordinator was also a vital to improving and growing our personalised care approach. This enabled us to improve care in other areas such as vaccination uptake or organising mental health reviews if needed at the same time.

Barrier 3 Failure to recognise that a person with a learning disability is unwell
While we found no evidence of this specifically we felt more confident we would pick this up with improved communication with patients and carers.

Barrier 4 Not enough involvement allowed from carers
The recording of carers for this cohort of patients was low at the start of our project and we focused on both communication of support and mechanisms to capture carers information. We already had a carers champion in our complex care team. We increased the number of LD registered carers from 89 to 310. This was an increase of nearly 25% of our overall carers register.

Barrier 5 Failure to make a correct diagnosis
Our reviews and work found no evidence of incorrect diagnosis

Barrier 6 A lack of accessible transport links
We were fortunate to start this work with a voluntary sector community car service in place. This was regularly booked and organised by our Health Connections social prescribing and regularly supported LD patients to attend their appointments. We found there were certain patients who were still not happy or able to travel and as a result we introduced a home visit service for some of our LD patients and visited an additional 10 patients in their homes

Barrier 7 A lack of joint working from different care providers

As part of our approach we made sure that LD patients were part of our Multidisciplinary Team (MDT) forum. This ensures when patients or their carers are known to ourselves and other services we can review jointly to avoid duplication of services and ensure wraparound care. This has resulted in improved communication with Somerset & Wiltshire Adult Social Care and the community learning disability nurses who now have a clear point of contact in the practice. In the 12 month period of our project this MDT approach ensured 2 patients were reviewed jointly with both our practice and local safeguarding teams

Barrier 8 Anxiety or a lack of confidence of people with a learning disability

We were able with the support of our care coordinator to set up specific clinics for vaccinations for those with LD. We also had some great examples where having a smaller team enabled us to provide support when it was needed to build confidence

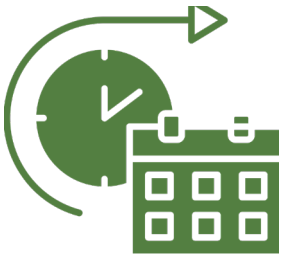
Barrier 9 Inadequate aftercare or follow-up care.

The nature of the project overall aimed to address this.
Did not attends (DNAs) are very common in this patient cohort.
We made some simple changes, including using Ardens templates to become more efficient at following up (DNAs) through running specific searches. These were all followed up with a call from our care coordinator to understand why appointments had not been attended.

We found the following:

- Recall letters for missed appointments had little or no impact on improving uptake and it was only phoning the patients and their carers which addressed lack of attendance. We also found this resulted in increased signposting to our health connections team for additional support as part of our wider practice approach to prevent loneliness and social isolation
- The easy read format of the invite and recall letters was not personalised enough, and this had caused offence for some patients.
- Some patients also reported that they felt offended by being asked to attend a learning disability health check as they did not perceive themselves to have a disability and they felt the nature of the invite did not meet their needs or help them understand why the check was needed.
- It was helpful to record a risk assessment on patient notes when identifying the best way to address complex care needs
- We quickly established there was a need for the care coordinator to focus more on understanding the patient perspective and also what they understood the health check was for.
- The LD coordinator ensured a more personalised service. Patients are now called before they receive a letter of invite and all patient letters are personalised in a format to suit. Follow up texts are also sent when appropriate as are day before calls to check they will be attending.
- The new LD coordinator has also ensured single oversight of the whole register and the number of health checks completed at any one point
- We record when we have listened to our patients with a coded LD diagnosis when they have declined a health check as they feel they do not need this, and they are functioning well very well in their chosen career or education pathway.

Future work



We want to extend our focus over the next few months to work more closely with our practice pharmacist and community pharmacists to do medication review with consideration to polypharmacy and appropriate reductions, medication adherence and monitoring where appropriate. Having access to the practice pharmacist during the LDs clinics when a medication regime may be complex, or the patient is struggling to manage medications.

We are also looking at developing some short videos that our LD patients can access prior to a visit to help them become more familiar with the practice.

Three Patient Stories which were identified as part of our work

Patient Story 1

Background and Situation
Patient A and his mother who is his carer were invited to attend for the annual health check. This was arranged over the telephone and no concerns were identified.

Previous letters in the patients notes indicated he can be agitated when visiting the surgery, we did not see this letter and there was no alert on EMIS. When he attended his appointment, he became very agitated and unintentionally grabbed at the nurse. The appointment was ended.

Assessment
The nurse spoke with his mum, and it became apparent since covid lockdown she had lost all MDT support for her son, a package of care and 1 day a week at day centre. Patient A has a single mother as his carer. She had been manging his challenging care needs for the past two years without support, this was causing considerable strain for the family. The mother had one friend in her social network and often felt socially isolated.

Recommendations, outcomes and actions taken
1. The complex care team reviewed how we called patients in for appointments and put in place more robust risk assessments at time of booking. For this patient medical notes were reviewed to ensure no relevant information was missed and appropriate alerts were added.
2. Immediate contact was made with the community mental health care teams and support reinstated for the family with the LD community nurses and psychologist.
3. Patient A was able to return to day centre and his package of care was restarted. This allowed his mother time for her to look after her own welfare, the LD psychologist is also now supporting her.
4. A referral was made to our Health Connection (social prescribing) team to help Patient A's mother overcome social isolation.
5. The complex care team developed a policy to ensure we ask specific but open questions to the patient, parent or carer relating to how the LD patient may feel when attending the practice or if a home visit, day centre visit would be more appropriate. Checks were put in place to assess if it is appropriate to speak with the parent or carer to avoid causing distress to the patient and to check if the patient is comfortable wearing a face covering when coming to clinic.

Patient Story 2

Background and Situation

The complex care team were contacted by the hospital asking for assistance to help get patient B to the hospital as he had not attended for a pre booked appointment.

We reviewed the LD register and could see he and his sister were called each for their Annual LD review but did not attend, it was also noted he did not attend for his annual diabetic health check for which he received a monthly prescription. When we tried to contact him via his telephone this was not answered.

Assessment

The Complex Care Team discussed this with the Health Connections, social prescribing team, and it was agreed Health connector would do a home visit to offer support and assistance to get to their appointments. The feedback from this visit highlighted many concerns as both the LD patients were struggling with day to day living. The home had inadequate heating, furniture, or beds to sleep in. There was evidence of damp and leaking roof in their home. Post was left unopened as both struggled to read or write. They had a mobile phone but were unable to recall the security setting to activate the phone and were anxious to answer it if it rang. They did manage to do their shopping but over or under shopped and struggled to understand how to use money. There was evidence of some medication stockpiling They were only just managing their personal care and may need support going forwards with this. They both lacked insight into their situation making them vulnerable.

Recommendations, outcomes and actions taken

With their permission a care plan was developed to support them:

1. Urgent referral to adult social care was made resulting in a package of care and an urgent review with a social worker and the housing team to manage the home difficulties, furniture and repairs were arranged.
2. Immediate support from community rapid response team who provided carers and an occupational therapy assessment while waiting for the ongoing package of care to start.
3. Urgent referral to the LD community health team was made to ensure they received an advocate and ongoing support.
4. Our Health Connector co-ordinated our local community cars - taxi service to get them to their appointments and worked closely with the social worker to get them a mobile phone they were able to use. It was also agreed with their permission we would contact them in writing and their carers would be allowed to open their post in their presence so that appointments etc were not missed.
5. We were able to book both their annual health check for LD. Patient B's diabetic appointment review was arranged and included a medication review and insulin teaching with the practice diabetic nurse specialist. A weekly blister pack was arranged with one of our local pharmacies. Hospital appointments as required were arranged with community cars to take him to his appointments and this was co-ordinated by his allocated Health Connector
6. To ensure continuity of care all the MDT are aware of the care plans that is in place and that the Complex Care Team and our Health Connection Team are a point of access. An alert was added to their medical records so other professionals can be aware.

Patient Story 3

Background and Situation

As part of the PCN role and the complex care role of follow up of patients on discharge from hospital we identified patient C who had a new diagnosis of cancer. We made a routine telephone call to offer support for their cancer care and to book required appointments and align medication as requested by the hospital at time of discharge.

As patient C felt unsure about his time in hospital and the diagnoses, we arranged to see him in the practice for a face-to-face appointment.

Assessment

Patient C found it difficult to understand what had happened in the hospital as his brother who supports him wasn't able to be there all the time due to covid restrictions. Patient C said, "he struggled with learning and understanding and that he went to a special school as a child, he did not like to be referred to as having learning difficulties as he felt embarrassed by this" There was no diagnosis of a learning disability on his medical records, and he had not been called in for an annual LD. At our appointment Patient C reported he is struggling to manage his care needs and his finance and would like help. He was worried about his medication as he struggled to read the boxes, receiving letters in the post worried him as they were often too complex for him to read.

Recommendations, outcomes and actions taken

With Patient C permission:

1. Our Health Connections team were able to meet with him at the time of our appointment and plan support for him working alongside an already allocated social worker and a package of care is in place to support him to manage his activities of daily living.
2. With gentle explaining he was happy for us to add a code of LD to his records, and he understood the reason and felt supported to be able to have an annual health review.
3. Patient C has the Complex Care Team and the health connections telephone number to speak to us should he have any concerns, an alert has been added to his medical records to indicate he needs letters in an easy-to-read format and that we have permission to contact his brother in relation to health care needs.
4. A referral was made to the community LD team, so they are aware of his care plan, but he declined contact from the LD team for now, this was respected.
5. His medication for his ease and safety were aligned in a weekly blister pack.
6. Ongoing cancer care support, LD appointments and support will be reviewed as required via the MDT supporting

Further Resources

Health inequalities - Learning Disability- Mencap https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. Lancet. 2014 Mar 8;383(9920):889-95. doi: 10.1016/S0140-6736(13)62026-7. Epub 2013 Dec 11.

Health Inequalities & People with Learning Disabilities in the UK: 2012
Eric Emerson, Susannah Baines, Lindsay Allerton

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