Care champions project

Challenging health inequalities for people with a learning disability

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Foreword

Chapter one of the NHS Long Term Plan makes personalised care business as usual across the health and care system. Surrey Heartlands Health and Care Partnership is committed to delivering personalised care, in parallel with addressing inequalities across the population it serves. Specifically, improving the outcomes of people living with learning disabilities.

This project was designed to develop Personalised Care Champions by increasing the skills and knowledge of people who are working directly with those living with learning disabilities. The teams set out to understand the impact of COVID identifying those health interactions that worked well during the pandemic and those that were less positive. Using lived experience, the project will help inform how to deliver services to people with learning disabilities which includes personalised health and care plans which are based on “what matters to me”, offering choice and control, achieving shared decision making and empowering people to live and age well.

The comprehensive model for personalised care delivery builds on our partnerships with local government, the voluntary and community sector and people with lived experience. This report demonstrates how personalised care for people with learning disabilities has been enhanced by the collaborative approach between learning disability providers, health partners and NHS England to test and learn from the experiences of people to improve outcomes. By working together with people who have shared their lived experiences, the project gives insight from the participants to inform improved interactions between people and their care providers. This report will add to the growing body of evidence, which shows that better outcomes and experiences, as well as reduced health inequalities, are possible when people have the opportunity to actively shape their care and support.

The project has been undertaken with enthusiasm and energy from service users and service providers and we are grateful to Avenues, Halow, Peak 15, Surrey Care Association and NHS England for their participation in the project.

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Key findings

- Staff played a vital role in lives of those they support, particularly when they were unable to see their families.
- Covid has shown how resilient people who have a learning disability and autism are, including those who have complex and multiple needs.
- There is a risk of deskilling people with learning disability by doing too much for them.
- The slower pace offered by the COVID-19 pandemic has broken down barriers allowing supported people to say how their day and lives should look. We need to learn from this and encourage supported people to have their say about their health. For example, testing allowed people to feel safe – this needs to be harnessed and transferred to other areas of health.
- There needs to be innovation in supporting people to take control of their health starting with the Annual Health Check, then to personalising the Health Action Plans to focus on ‘what matters to me?’ and ‘how can I become more independent?’

Context

Health inequalities for people with learning disabilities have been well documented. Inequalities often begin in early in life, and can result from barriers in accessing timely, appropriate and effective health care.

- On average, the life expectancy for women with a learning disability in Surrey is 22 years shorter and for men 11 years shorter than the general population. (*Surrey Heartlands LeDeR 2021*)

- 38% of people with a learning disability die from an avoidable cause compared to 9% in general population.
(*NHS Digital 2017*)

- In line with the national picture, respiratory, circulatory, and cancer-related conditions are the most common cause of death in those with learning difficulties.
(*Health Inequalities Faced by People with Learning Disabilities in Surrey Heartlands*)

The NHS Long Term Plan sets an ambition that by 2023/24, at least 75% of people aged 14 or over with a learning disability will have had an annual health check. This is a prevention measure, which helps people who can find it hard to know they are unwell or tell someone about it to stay well and access appropriate care. However:

- 55% people with learning disabilities accessed their Annual Health Check (AHC).
- 44% people with learning disabilities received their flu jab.
- 7% of people with learning disabilities only were offered a copy of their care plan.
(*NHS Digital (2019). Health and Care of People with Learning Disabilities: 2017-18. Health and Social Care Information Centre*)

In Surrey, the proportion of people with learning disabilities receiving Annual Health Checks has increased by 54% (from 48% to 75% between 2019/20 and 2021/22).

However, this has not consistently translated into an increase in the proportion of people with learning disabilities receiving facilitated interventions because of their Annual Health Check.

In fact, between 2019/20 and 2021/22, there was a decrease in proportionate take-up of the following interventions:

- Blood lipid test (78% to 62%)
- Assessment of nutritional status, diet and level of activity (34% to 30%)
- Medication intervention for raised blood pressure cohort (46% to 38%)

The only marked increase was in relation to the prediabetic cohort of people with learning disabilities receiving a lifestyle intervention.
(Health Inequalities Faced by People with Learning Disabilities in Surrey Heartlands)

The COVID-19 pandemic has further highlighted the inequalities people with learning disabilities face, for example, they are more likely to contract COVID-19, have a more severe case of COVID-19, and are four times more likely to die from the illness than the general population.
(Public Health England 2020).

Our aim

We set out to gain lived experiences of those with a learning disability during the first year of the COVID-19 pandemic. In particular, we wanted to understand their experiences of accessing health care and how the pandemic impacted their wellbeing.

Using this feedback and working with those who support them, we evaluated the effectiveness of Annual Health Checks for people with learning disabilities to understand how they can be developed to improve their health and wellbeing. With this is in mind, we wanted to look at the role of personalisation for care plans to empower people with a learning disability to focus on ‘what matters to me’.

The initiative

Collaborating with Avenues, Halow and Peak 15 - providers of day-to-day support for people with learning disabilities, eight focus groups were established.

Each focus group brought six to eight people together for two sessions. The first focussed on the experience of COVID-19 and a second on the provision of healthcare.

Using feedback from these groups, staff and managers from Avenues and Halow developed Action Learning Sets.

Outcomes

Experience of the COVID-19 pandemic

We asked focus groups…

What has been the worst thing about Covid?

- “Not going out and seeing family and not going to day services”
- “The worst thing about it was not being able to go home and see my family”
- “Trapped in doors”
- “Masks have made it difficult to understand - voices get mumbled”
- “I hate social distancing”
- “Locked in, not seeing friends not going to club”

What has been the best thing about Covid?

- “Feeding the ducks”
- “The best thing is we’ve got loads of staff here and doing games”
- “Baking”
- “Zoom film nights and discos”
- “I was taught how to knit”

What helped during Covid?

- “Having the vaccine”
- “For us two it was to be together, at least we had each other”
- “Staff helped and explained what was going on and I understood the situation and what was going on”
- “Testing makes me feel safe”
- “I painted things”
- “Cooking”
- “Staff help us out to get tests done”
- “Staff helped me a lot”
- “Staffed helped and people we live with helped a lot”
- “Good to have staff around us to help us out”

Staff told us…

“We watched the news and daily briefings with people we support and did our best to explain it. It was a real test of current affairs.”

“I remember changing my clothes in the garage before entering the home to stop the virus.”

“I remember regularly thinking ‘we can’t do this… I am out of my depth.’”

“We realised how important we were to the people we support particularly when they couldn’t see their families.”

People with a learning disability felt trapped and some became quite fixated on why they couldn’t go out.

- They missed friends, family, and usual actives like work and clubs. For staff, there was much anxiety about working in homes at the start of the pandemic. Concerns about taking the virus into the workplace and then back to their own families.

Feelings of guilt were widespread.

- Staff who worked at home felt guilty, staff who tested positive felt guilty, staff on long term sick or had to shield felt guilty.

Staff found it hard to see those they support struggle with the situation.

- The focus quickly became to keep everyone safe and engaged. The pace in both residential care and supported living slowed. Residents took advantage and tried new things such as art, cooking and baking. Exercise was key and many took advantage of the great outdoors, walking and experiencing nature. Staff worked creatively and introduced ‘Zoom’ film nights and discos. The slower pace allowed support workers to take time and work on a one-to-one

basis with those they support. They helped residents learn new life skills such as cooking, baking, gardening, hoovering and doing laundry.

- The role of staff was pivotal to the lives of those they support. Assistance to wear PPE and carry out tests was crucial. Whilst it was clear that residents didn't enjoy wearing masks or testing – it made them feel safe. Help by staff to understand the changing regulations was key. The news was not always helpful to either residents or staff. For staff, news reports often conflicted with provider policies. For residents, the inequalities of tier systems and lockdown rules caused contention and people struggled to understand why some people had more freedom than others.

Supporting people who are non-verbal.

- This was a similar experience of those working with people who are non-verbal. Whilst some supported people were not able to fully understand what was happening, they showed no signs of anxiety or stress. In fact, some progressed better than they did when going to day services. Staff found they had more quality time to spend with those they support, teaching them new life skills.

Provision of health care and Annual Health Checks

We asked the focus groups …

Did you have an Annual Health Check with the doctor?

- "Health check done over the phone – not sure how long they lasted – not sure what was asked."
- "Long time ago – not sure if went to GP."
- "Would have been better to see the Doctor."
- "It was good, it was a normal health check with the GP."
- "I had my health check. It was alright I think. I spoke but didn't quite understand – on the phone."

Do you have a health care plan?

- "I think it's in my folder"
- "Err – not sure"
- "Do have a plan, I just have got one"
- "It's a plan about people that we want in our lives and people we don't want in our lives"
- "Once it's completed, we will get a copy, it's done on the computer and printed off"

A key ambition for the NHS Long Term Plan is for at least 75% of people aged 14 or over with a learning disability to have had an Annual Health Check. Annual Health Checks are carried out by GPs or a health professional and measures weight, height, blood pressure as well as underlying health conditions such as diabetes. Checks for more specific conditions such as Dysphagia, constipation and foot health should also be made.

Access to healthcare during the pandemic was mixed with people reporting that opticians were the easiest to access. GP appointments tended to be over the phone and there was very little access to dentistry. Annual Health Checks were largely conducted over the phone, making them difficult to understand. Support workers echoed this, reporting that when the checks were done, there was little point to them. However, some residents found a video appointment useful, particularly those who find attending appointments distressing.

Health Action Plans are completed by care settings taking into account the thoughts and opinions of supported people. It is clear that whilst Health Action Plans are in place for residents there was little knowledge of what they are, what they contained or where they are kept. Supported people did not really know how to access them.

Key learning form Action Learning Sets

“We have learnt that people who have complex and multiple needs are more resilient and can be more independent than realised.”

“Covid has shown us that we can deskill people. We do it to or for people rather than with them.”

“People with autism coped brilliantly as we set new routines.”
“Barriers came down, and people we support were more open. They were telling us how their day should look.”

The pandemic has allowed support workers and those they support time to revaluate their lives. People with complex and multiple needs are more resilient than first thought and many staff have felt that they may have de-skilled those they support by doing too much for them. The pandemic has encouraged independence and supported people have thrived.

Going forward

It is clear that people with a learning disability want to take control of their health and would like the skills to do this. Support teams have concluded that they need to look for innovative ways of improving uptake and quality of the Annual Health Checks.

Training and education for support workers

Training and materials should focus on:

- Helping people prepare for health checks focussing on what matters to them.
- Ownership from the start – supporting people to make their own appointments at a time that suits them.
- Support to prepare people for appointments so that they can say how they are feeling and what they want from the appointment?
- Discussing the outcomes of appointment - how do they feel, what/how do they want to take any concerns/issues forward?
- Talking about medicines - what are they for, how do they wish to take/administer them?
- Talking about what was said - any referral/follow-up appointments. Support to make sure they happen.

Training and materials for GPs by people with a learning disability

- Creating an understanding of the challenges faced by those with a learning disability in accessing health care.

Documentation

- Move away from lots of paperwork, keep it simple and easy.
- Don’t keep it in the office, make it accessible.
- Electronic formats so that people can use technology
- Under all of the sections of the Health Action Plan add:
- ‘What do I want?’
- ‘How can I become more independent?’

Supporting people who are non-verbal

Whilst supporting those who are non-verbal make their own health choices is more challenging, it is not impossible.

Getting to know what people who are non-verbal like and don't like and documenting this is important. Looking for trends and trying out solutions with them is one way of supporting people.

Conclusion

The experience of living through the pandemic has resulted in many positive, unexpected outcomes, both for those being supported and their staff, with a new understanding and respect emerging of the resilience of both.

There is much opportunity in sharing this report and the recommendations across the system within Surrey. Complimentary and aligned pieces of work can come together to develop integrated recommendations, such as the quantitative analysis of Annual Health Check data completed by the system convener, the audit being completed by our LeDeR lead into the quality of health checks and system work about the health and wellbeing of social care workers. The growing body of evidence referenced in the introduction is expanding and contributing to a rich pool of evidence within Surrey.

If we are truly to empower people with learning disabilities and autism in all areas of their lives, including their health, access to an excellent quality Annual Health Check, in a manner of their choosing for which they feel well prepared will enable meaningful Health Action Plans. This combined with the right support by trained and knowledgeable staff with a holistic outlook including healthy living, will contribute to driving down the stark health inequalities faced by people with learning disabilities.

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Produced in association with:

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