Supporting people with learning disabilities and needle phobia

Using desensitisation and reasonable adjustments to improve vaccine access and uptake

Neena Kochhar: Senior Community Learning Disability Nurse and
Mark Sheen: Consultant Nurse & Clinical Services Manager
Hounslow Adult Learning Disability Health Team
West London NHS Trust

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Source article: Kochhar N, Straiton R (2024) Supporting people with learning disabilities and a fear of needles to receive the COVID-19 vaccine.

Background

COVID-19 vaccination clinics were held between May 2021 and May 2023. The service provided 24 COVID-19 vaccination clinics to people with learning disabilities on the desensitisation programme. This allowed the service users to have their 1st, 2nd and 3rd dose of vaccine.

- Many people with learning disabilities have a fear of needles, to the extent that it can affect their ability to receive certain healthcare interventions.

- Heslop et al (2013) reported that one sixth of people with learning disabilities had a fear of contact with medical professionals, including a fear of needles. Heslop et al (2013) proposed that some of these fears could be addressed through desensitisation work.

- High mortality rates among people with learning disabilities during the coronavirus disease 2019 (COVID-19) pandemic highlighted the issue of health inequalities.

Article detail: background, key points and rationale; statistics reported from sources cited in the article.

Factors influencing programme development

When people with learning disabilities were provided with access to the national COVID-19 vaccination programme, it did not meet all the access needs of this population group, since no special arrangements were made for those who feared medical environments and equipment

Mainstream services not having appropriate resources or sufficient time to undertake in-depth work with those who wanted the vaccine but had a fear of needles

Another factor that needed to be considered was the emerging national discussion on whether unvaccinated people with learning disabilities can access broader community services

Families wanting their loved ones vaccinated and had growing concerns as this group was being denied the vaccinations

How to support this vulnerable group of people.

Desensitisation programme

- A bespoke desensitisation programme was developed to expose people with learning disabilities gradually to needles and reduce fear and anxiety with the aim of receiving (COVID-19) vaccines

- Desensitisation is a technique used to develop tolerance by gradually exposing the person to a particular stimulus over a set time to reduce fear and anxiety

The participants of the programme:

Of the **47** eligible people,

- **5** did not engage
- **3** were exempt from vaccination
- **5** had capacity and declined
- **5** received the vaccination before the programme commenced
- **29** people consented to participate in the programme

The cohort was subdivided into two groups:

- A desensitisation programme group (24 people) had a **fear of needles**
- A **reasonable adjustments** group (five people). Did not have a fear of needles but required familiar people, people who would not leave home environment and would not allow people they did not know into their home

How the programme was developed

Model: learning disability nurse + PBS practitioner

The learning disability nurses and positive behaviour support (PBS) practitioners in the community health team collaborated to develop the desensitisation programme.

Identify eligibility → **Prepare home visit** → **Build rapport** → **Repeat trials** → **Vaccinate when ready**

Identify Eligibility

To be eligible for the programme, the person needed to:

- Have a confirmed diagnosis of a learning disability
- Live in the borough
- Have a locally registered GP
- Not have received the COVID-19 vaccine due to a fear of needles

Prepare home visit

Before the programme commenced, a PBS practitioner and nurse contacted the person or their primary carer to complete clinical documentation and provide them with resources explaining the desensitisation programme.

This documentation included:

- an assessment
- treatment consent form,
- general guidance on preparing for the visits
- social stories and easy-read visual materials

Article detail: desensitisation programme approach and eligibility sections.

Based on Kochhar & Straiton (2024), Learning Disability Practice

How the programme was developed

Model: learning disability nurse + PBS practitioner

Identify eligibility → **Prepare home visit** → **Build rapport** → **Repeat trials** → **Vaccinate when ready**

Build Rapport

- The focus of the first visit was to develop a positive rapport with the person
- Three further visits per week were then arranged and the desensitisation programme implemented
- Three visits per week over a month period, totalling to 12 visits

Repeat Trials

- If the person made progress during the programme, the frequency of the visits each week was maintained until the vaccine was administered
- The programme was reviewed and adjusted if the individual required more time

Article detail: desensitisation programme approach and eligibility sections.

Based on Kochhar & Straiton (2024), Learning Disability Practice

How the programme was developed

Model: learning disability nurse + PBS practitioner

Vaccinate when ready

Health interventions can trigger distress and trauma especially if previous interventions, for example blood tests or injections, did not go well

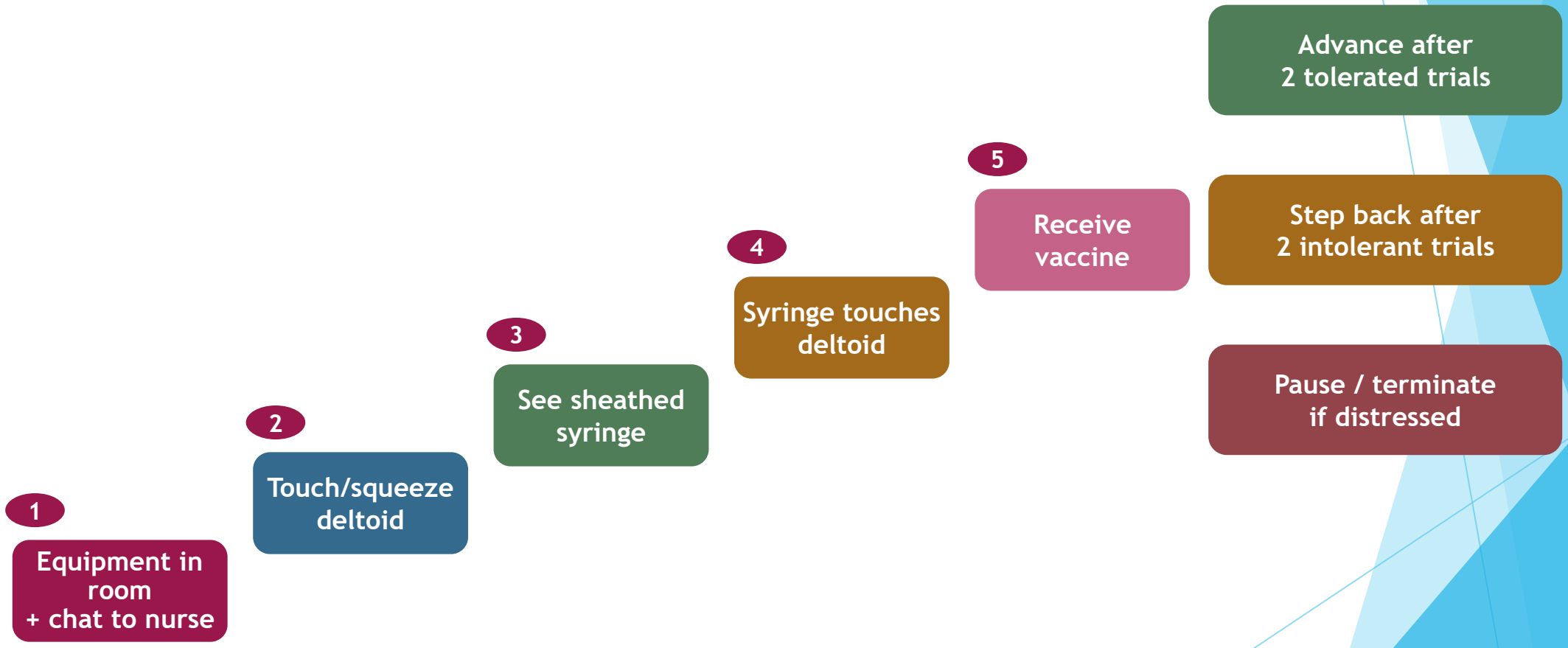
In accordance with trauma informed care that seeks to eliminate the anxiety and triggering environment around receiving care for those with trauma (Bridging Freedom 2022), if the person showed signs of distress during the programme's implementation, the team used their clinical judgement to either pause or terminate the programme for that day, therefore avoiding re-traumatisation. If the programme was not progressing over subsequent visits, the programme was terminated indefinitely

Article detail: desensitisation programme approach and eligibility sections.

Based on Kochhar & Straiton (2024), Learning Disability Practice

The core mechanism: gradual exposure

Small steps. Clear criteria. Stop if distress emerges.

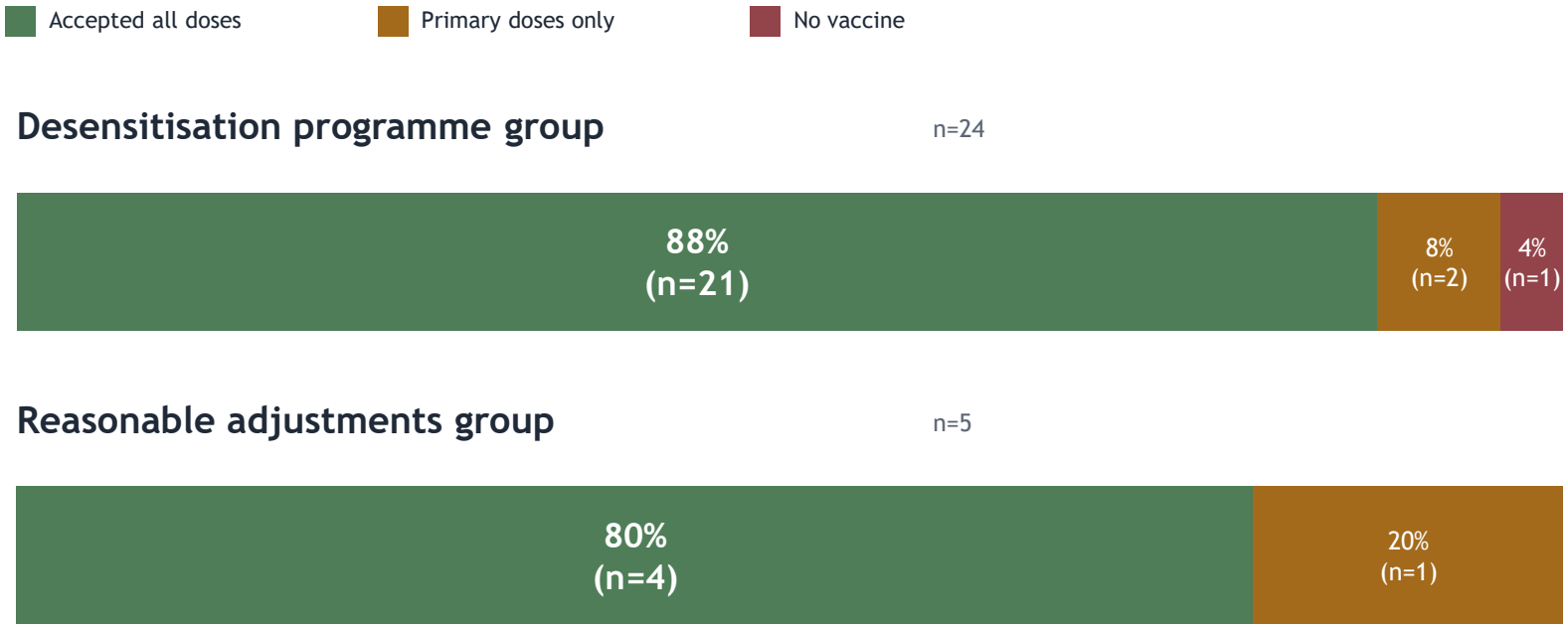


Article detail: Box 1, Box 2 and Figure 1 programme protocol.

Based on Kochhar & Straiton (2024), Learning Disability Practice

Outcomes

Most participants received all doses.



Article detail: outcomes section, Figures 2-3, and case studies.

Based on Kochhar & Straiton (2024), Learning Disability Practice

Challenges encountered

Labour intensive. At its height, **60 hours per week** of collective clinical time was allocated to this programme

Additional clinical work/tasks had to be completed outside of the programme:-

- Conducting mental capacity assessments
- Attending best interest meetings
- Collecting COVID-19 vaccines from different locations
- Arranging prescriptions for sedation or topical anaesthetic cream
- Court of Protection related work

Completing this work was a priority since it ensured the smooth running of the COVID-19 vaccination clinics. However, it sometimes created additional time pressures for the healthcare professionals involved

Challenges encountered

- **People being sceptical:** Some primary carers were sceptical of the programme because other healthcare professionals had been unsuccessful in administering the COVID-19 vax previously

- **High staff turnover:** (in some care homes), new carers were sometimes unprepared for visits, as they needed to familiarise themselves with the process involved

- **Court of Protection:** There were a few cases which required input from the Court of Protection due to family opposition to the COVID-19 vax. Various Best Interest meetings/discussions took place. Work commenced with the Trust's solicitor (with bespoke vax programmes being formulated and submitted as part of the Court application). The team were required to be compliant with Court rulings in administering COVID-19 vax by set dates)

Practical takeaways for services

Build reasonable adjustments into the default clinical pathway.

1	**Screen early**	Ask about needle fear, past trauma, communication needs, sensory needs and preferred routines.
2	**Adjust before the visit**	Use easy-read information, social stories, home visits, quiet slots and longer appointments.
3	**Use familiar people**	A trusted vaccinator or nurse can reduce threat and improve cooperation.
4	**Break the procedure down**	Use repeated graded exposure, preferred reinforcers and clear tolerance criteria.
5	**Stop safely**	Pause or terminate if distress emerges. Avoid re-traumatisation.

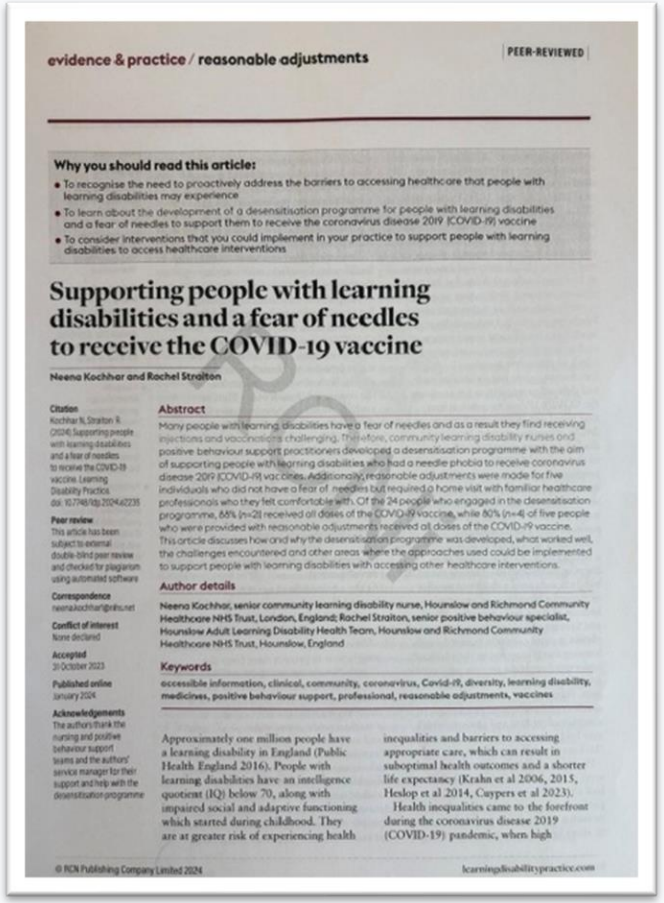
Article future implications: reasonable adjustments include double appointment slots, easy-read materials, jargon-free sentences, positive rapport, praise and rewards.

Legacy and what next?

- **Flu vaccine programme:** Bespoke support is offered with the flu vaccine administration
- **Phlebotomy:** Improved working links with phlebotomy service (inc joint working)
- **District nursing service:** Improved links district nursing service (inc joint working)
- **Referrals:** Emphasis (request for support) has moved onto drawing blood for multiple blood samples
- **New technologies:** Open to new technologies/approaches such capillary vs. venous samples (TAP no longer available, TASSO/other)

The work continues!

Any questions?



evidence & practice / reasonable adjustments

PEER-REVIEWED

Why you should read this article:

- To recognise the need to proactively address the barriers to accessing healthcare that people with learning disabilities may experience
- To learn about the development of a desensitisation programme for people with learning disabilities and a fear of needles to support them to receive the coronavirus disease 2019 (COVID-19) vaccine
- To consider interventions that you could implement in your practice to support people with learning disabilities to access healthcare interventions

Supporting people with learning disabilities and a fear of needles to receive the COVID-19 vaccine

Neena Kochhar and Rachel Straiton

Citation
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Peer review
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Correspondence
neenakochhar@nhs.net

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Abstract

Many people with learning disabilities have a fear of needles and as a result they find receiving injections and vaccinations challenging. Therefore, community learning disability nurses and positive behaviour support practitioners developed a desensitisation programme with the aim of supporting people with learning disabilities who had a needle phobia to receive coronavirus disease 2019 (COVID-19) vaccines. Additionally, reasonable adjustments were made for five individuals who did not have a fear of needles but required a home visit with familiar healthcare professionals who they felt comfortable with. Of the 24 people who engaged in the desensitisation programme, 65% (n=21) received all doses of the COVID-19 vaccine, while 80% (n=4) of five people who were provided with reasonable adjustments received all doses of the COVID-19 vaccine. This article discusses how and why the desensitisation programme was developed, what worked well, the challenges encountered and other areas where the approaches used could be implemented to support people with learning disabilities with accessing other healthcare interventions.

Author details

Neena Kochhar, senior community learning disability nurse, Hounslow and Richmond Community Healthcare NHS Trust, London, England; Rachel Straiton, senior positive behaviour specialist, Hounslow Adult Learning Disability Health Team, Hounslow and Richmond Community Healthcare NHS Trust, Hounslow, England

Keywords

accessible information, clinical, community, coronavirus, Covid-19, diversity, learning disability, medicines, positive behaviour support, professional, reasonable adjustments, vaccines

Approximately one million people have a learning disability in England (Public Health England 2016). People with learning disabilities have an intelligence quotient (IQ) below 70, along with impaired social and adaptive functioning which started during childhood. They are at greater risk of experiencing health inequalities and barriers to accessing appropriate care, which can result in suboptimal health outcomes and a shorter life expectancy (Krahn et al 2006, 2015, Heslop et al 2014, Cuypers et al 2023).

Health inequalities came to the forefront during the coronavirus disease 2019 (COVID-19) pandemic, when high

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Short film of the desensitization programme
(follow needle desensitization programme link)

LINK: Adult learning disability health team :: West London NHS Trust