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 **Sussex Parent Carers Covid -19 Vaccine Survey January 2021**

**Introduction**

This report details the findings of a snapshot survey of parent carers of children and young people (CYP) with Special Educational Needs or Disabilities (SEND) on the subject of the Covid-19 vaccination. The survey ran 14th December to 14th January 2021 across Sussex and received 97 responses. Parent carers were asked 3 questions:

1. What information would you like to receive about the Covid-19 vaccine itself, or how it will be administered?
2. What would you like your GP or other health teams to consider (and provide for) when offering the vaccine to you and your CYP with SEND?
3. Do you have any concerns about the vaccine?

This report has been requested by, and is being shared with, the NHS in Sussex to inform the local rollout of the vaccination programme. We are also escalating findings that relate to national policy around the vaccine, asking that these are taken on board by the Joint Committee on Vaccination and Immunisation. We are very grateful to those parent carers who responded to the survey and will share updates on how these matters progress in coming weeks.

**Key summary findings and recommendations**

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|  | The level of concern about the Covid-19 vaccination in the SEND parent carer community is mixed. 50.5% parent carers are not concerned, 5.2% have some concerns and 44.3% are concerned |
| Clock | Parent carers are mostly concerned about when they/their CYP will be vaccinated:* Parents want to know when they/they CYP will be vaccinated, including understanding what progress is being made in vaccine trials for under 16 years olds
* Parents request that CYPs aged 16-25 who are vulnerable due to their SEND are prioritised to receive the vaccine
* Parent carers expressed concern that they might fall ill themselves while awaiting the vaccine, preventing them from being able to care for their CYP. While parent carers are to be prioritised for the vaccine in group 6, greater clarity is needed as to how they will be identified and called forward by their GP
* With PAs recently being brought into priority group 2, parent carers should also be included within this cohort
* Families would prefer that a whole family can be vaccinated together, not only would this be more convenient and help minimise infection, but because CYPs will respond positively to role-modelling by their parents receiving the vaccine
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| **C:\Users\Sally\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\D77D006A.tmp** | Parent carers want to better understand the vaccination programme:* Nearly ¼ of parent carers are concerned about the potential side effects of the vaccine on them/their CYP, especially those with a health condition
* Parent carers would like to receive objective information which explains the benefits vs the risks of being vaccinated, including any potential side effects/reactions, the efficacy of the vaccine especially on different strains of the Coronavirus/how long the protection lasts, and the different types/content/dosage
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| Separation Anxiety Disorder in Children | Parents are very concerned how their CYP will cope with the vaccine appointment and having an injection* People administering the vaccine need experience / understanding of SEND, or even better the CYP’s needs and how best to support them
* An alternative to the injection for those CYP who are needle phobic is needed
* Parent carers must be able to attend/support their CYP at vaccine appointments
* The unusual medical environment may be intimidating and frightening; quiet/private spaces would be preferable for anxious CYPs. Some parents enquired whether more familiar settings could be used, eg schools
* Vaccination appointments need to be available without time pressures, recognising CYP with additional needs may need longer slots/not to feel rushed/receive appropriate amounts of notice etc
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| Communication Icon - Communication (1000x1000), Png Download | Parent carers request that inclusive communication is used to reduce anxieties and build understanding about the vaccine:* Visual aids and a social story will help address fear of injections and pain
* Health practitioners need to be able to communicate with CYP with SEND, to provide reassurance and support when administering the vaccine
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 **Detailed findings**

Pages 3-6 detail some of the typical answers parent carers gave in response to the two main questions in the survey. The bullet pointed comments are direct quotations which provide rich insights into the views of parent carers.

**When will I/we get the vaccine:** who is being prioritised/when we will find out

* Can I be moved up the priority list as I am the mother/carer of a child aged 11, diagnosed with Autism, Anxiety and sensory needs and has an EHCP recently approved but we do not claim DLA.
* Why are people with learning disabilities not on the priority list? Evidence shows that individuals with learning disabilities are at much greater risk yet the government and LAs appear not to be concerned by this - are deeply concerning for families.
* Can the whole family be vaccinated at the same time?
* When as a single parent with a child with autism and his carer (don't get carers allowance though as I work) will I get the vaccine? If I went down with Covid it would be horrendous. I am my son’s only person.
* When will it be available for children? How many trials have been undertaken on under 16s?
* When will children under 16 with underlying health conditions and SEN will be vaccinated? SEND children don't follow rules and therefore are more likely to get Covid. I think all school age children should be vaccinated so the virus can't keep mutating and school children don't socially distance. It is madness not to vaccinate children.
* What provision for children not in school (shielding or education at home)?
* We have 3 disabled children but it says only the main carer will get it. We both have to jointly care for our children but as my husband also works full time he doesn't qualify.
* Priority: If I die or I am permanently severely disabled, then my disabled child could cost the LA £100,000 per year in residential costs.

**Side effects**

* What to look out for
* Short and long-term side effects
* Data on safety, allergies, when medical advice should be sought
* What the chances are of getting a mild version of symptoms after taking the vaccine
* What the likely hood is of anaphylactic shock is after first injection? Will I be able to still care for my son after vaccine, i.e is it a live vaccine?
* Safety checks on each cohort eg age, disability, sex

**General information:**

* Plain English summary of differences between each vaccine
* A clear, short outline of why the vaccine is a good thing will encourage take up
* Info on risks and benefits
* A balanced and objective view of benefits versus risks for my young people, without pressure to go down any one route

**How is the vaccine administered?**

* Can it only be administered via injection? Any plans for oral administration for children?
* Is person administering it qualified to do so?
* What happens if you need to take your child with you? What is the set up like? What is the process? If I had to take my son with me, he would need to know what was going on/what will be happening etc, even though it's not him having the vaccine
* Will I be able to attend with my child as his anxiety would mean that he would not cope with the vaccine without support?
* What about those who are needle phobic

**Contents of vaccine/differences between them/dosage**

* Which version of the vaccine will I be offered? Why are there 3 different types of vaccine? Why not just use the best one for everyone? How can I be reassured that I will revive the 2nd dose of vaccine in a timely manner as per manufacturers recommendations?
* Dosages as recommended by manufacturer will be assured, not mix and match of different vaccines, or differing periods between doses to that recommended.
* Which version of the vaccine, how many doses, the wait in between, what happens if 2nd dose becomes unavailable?

**Where will the vaccine be administered?**

* How local will it be?
* How crowded?
* Will there be parking?
* Will it be our GP practice?
* Where to administer ie a football stadium is not accessible to everyone

**CYPs’ needs during administration**

* Honestly we have no idea how we will manage to get 1 of our ASC sons to accept 2 injections in a setting other than home. He'll panic, scream his head off, possibly try to leave.
* How my child who is needle phobic will receive it.
* Needs to be in private with parents being done at same time as my son will resist, he needs to see it's nothing to worry about, but needs to not be in a public place in case he has a meltdown.
* Nasal spray options
* Child-friendly explanation including understanding of sensory issues/GP-anxiety
* Where, will it be in a private room? In case our ASC son has a meltdown. Can our son watch his parent be vaccinated this would ease his anxiety and have his straight after? Needs to be quiet area, not lots of people making noise or crying.

**Efficacy of vaccine**

* Will it protect against latest identified strain/s, what is the efficacy rate, how will we know we have made antibodies (any plans for a follow up antigen test?)
* Will it prevent me/immunise me from getting covid?
* Will it stop me from being infected and infecting others? Will it work against different strains?
* How frequently will I need to have one, eg annually for life? Every 5 years etc..?

**Concerns around people on medication/with specific health conditions**

* Will Auto Immune conditions be identified and an appropriate alternative provided
* My son has a chromosome deletion will this affect how the vaccine works

**Will it be mandatory to have the vaccine in order to access any part of life**

* Will I be socially punished if I don't have it
* Will I have to have it to travel in the future?

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**Timing of vaccine appointment**

* No time pressure; that we might need extra time to get the vaccine done; being patient
* Separate appointments from other patients, at quiet times rather than open Saturday clinic as too overwhelming and also more of an infection risk factor.
* Choice of appointments to suit mood of the child ie if it's an anxious day postpone appointment and not get put to the back of a list. May take several attempts
* No long waiting time
* Sufficient notice period

**Awareness of and sensitive to needs**

* About her anxieties about appointments and having an injection
* My son with SEND is needle phobic and will be very anxious and likely to refuse having a jab. Inability for him to tell us he's unwell
* Be aware of autism and all connected conditions and make sure they know how to deal with children when having the vaccine
* That it will be extremely distressing for him so to keep discussions to a minimum and be as quick as possible obviously making sure it's done safely
* The unusual and necessary medical environment may be intimidating and frightening
* Having it given by people with a good experience of dealing with special needs is essential to understand and to be given enough time for the person to calm and deal with the anxiety of having the vaccine or any jab
* Understand the CYP’s capacity when explaining information to them, if they are anxious and cannot cope with the information/situation be kind to the parent.

**Support for CYP with additional needs to access/tolerate the vaccine**

* Heightened sensory needs mean only liquid or nasal puff medication tolerated, how will this be managed for needle and hospital phobic child?
* Was unsuccessful encouraging child out of the house to go for flu jab and was unable to attend last minute. What help will be available to support a child with these difficulties, particularly as they will need another dose a couple of weeks later.
* That they may not want it - could cause school refusal and anxiety
* What will be offered for young people who cannot cope with injections? Sedation possible at surgery where needle phobia?
* That the young person may not be able to consent due to learning disabilities
* Offering Emla cream to numb the area.

**Appropriate adult(s) present**

* My son needs 2 people with him to help him keep still - we need to know that this is ok

**Identifying us carers**

* How do they know we are carers?
* What do we need to do to let them know?
* How will they communicate this in advance to make sure they know of everyone who is in that priority group?

**Family appointments**

* That we can be vaccinated at the same time - he's more likely to agree if I have it too! Plus will cut down the number of appointments as I would need to go with him anyway
* To create a family herd immunity (like flu)

**Information/communication**

* Sensory appropriate explanation ("we understand that GP visits can be overwhelming"), advising of nurse name/environment/procedure before appointment. Nurse practitioner understanding SEN/sensory behaviour
* Speak slowly and maybe use visual aids/story.... in other words use inclusive communication
* Fear of injections and pain and reassurance to the child
* Explaining side effects if any and whether my child will be safe to go back to school once first jab administered

**Consider specific requests around who administers the vaccine**

* Local GP to do it would be good
* Allowing our son’s Aunt to administer it at our home. She's a qualified nurse who has experience in such as she used to be a school inoculation teams nurse.
* I want specialist Cystic Fibrosis units/centres to be able to offer the vaccine to their Cystic Fibrosis patients and be able to revisit in the familiar setting of their usual clinic

**About the survey respondents**