

Understanding vaccine motivations and barriers for disabled children and young people

DOCUMENT PREPARED FOR MOH

Background to the research

- The vaccine roll out for children aged 5-11 is scheduled to commence in mid-January 2022 across community vaccination sites, primary care settings, and in some cases at school based pop-up clinics.
- To ensure equity and fairness in the roll out, barriers that exist for disabled children and young people need to be identified and addressed.
- The focus of this research is capturing perspectives of parents of 5- to 11-year-old disabled children including 'invisible' disabilities for example neurodiverse young people, young people with learning disabilities, and young people who have challenges with communications.
- This research will be used to inform:
 - Communications and education strategies for the rollout
 - Mobilisation strategies
 - Inform policy, practice and service provision

What do we want to understand?

The research objectives:

1. **Understand health decision making dynamics generally** – How are health decisions including vaccinations made? The role of the parent and child in decision making, including any other influencers. What information is sought out and how is it used? Any tools and techniques that parents and whānau use to communicate health care decisions with their children?
2. **Explore any motivations that exist for parents to get disabled children and young people vaccinated**
3. **Identify key barriers and inequities that exist for getting disabled children and young people vaccinated** – both physical (site access) and perceived (child's comfort)
4. **Understand interventions that can overcome barriers or leverage motivations towards getting vaccinated** – including how we can use communications, messages, influencers, or other means to influence parents to get disabled children and young people vaccinated
5. **Understand the ideal vaccination experience and what a good vaccination service looks like** for a young person with disabilities. Are there any different requirements? By type of impairment?
6. **Bring it all together** with a clear roadmap on how to encourage parents of disabled children and young people to get vaccinated

The approach

- 10 x 1 hour depth interviews with parents/caregivers of 5-to-11-year disabled children
- Engaging with parents was seen as critical in this process as they are a key decision maker (particularly in instances where parental consent is required).
- Across the sample we recruited for a mix of ethnicity (including Māori, geographical regions and social deprivation).
- All parents had to have some hesitation about getting their child vaccinated (although anti-vax was screened out- i.e. the parent/caregiver was vaccinated or in the process of getting vaccinated) – we recruited for various degrees of hesitation across the sample
 - Mix of disabilities: 5 x parents of children with ‘invisible’ disabilities including learning disabilities, and young people who have challenges with communications (for example: dyslexia, ADD, depression, OCD, bipolar, autism spectrum, cystic fibrosis, diabetes).
 - 5 parents of children with ‘visible’ disabilities (for example: Down syndrome, wheelchair users, visual impairment, paralysis, cerebral palsy)
- Note: the community is diverse – language used throughout this document reflects the language of the people interviewed.

SUMMARY OF FINDINGS

For parents, the primary motivations for their child to be vaccinated is to protect them against Covid and avoid transmission to others

- Parents want their child to be safe, and many parents feel that their children are at a heightened risk from the effects of Covid due to compromised immune systems.
- Helping to stop transmission of Covid to others is also a consideration – some parents live in communities with strong anti-vax sentiments, others have vulnerable elders at home, and cringe at the thought that they or their child could be responsible for spreading Covid.

“They are already at a higher risk because of their compromised immunity, getting Covid could mess up their blood sugars and complicate things considerably”

- Diabetes. NZ European

A secondary motivation is to ensure their child can participate fully in everyday life and not be excluded

- Parents do not want to limit their child’s interactions in daily activities because they are unvaccinated.
- Some parents worry that unvaccinated children may have to be home schooled or not allowed to go to the local after school programme etc. Limited access to daily routines would put a lot of pressure on the whole family and would be a significant compromise.

The coming storm of cases from Omicron is a strong nudge to getting the vaccination

“Covid will be rampant soon, so the vaccine is some sort of protection and in my mind that should be enough of a motivation but emotionally I am still uncertain, it will take a leap of faith”

- Autism spectrum, vision impairment, inherited/genetic condition. Māori / NZ European

Parents are motivated, so how do they go about making the decision to get their child vaccinated?

Decision-making around general health issues for their child can involve several people

- In general, health decision making often involves a team of trusted others like teachers, teacher aids, counselors, specialists, family and friends, and a lot of open discussion to assess what is working and what needs to change. The process can be lengthy, disruptive and time consuming.

For vaccine decision-making, the unit is tighter – typically, involving just the GP and the child

- As it is a one-off and shorter experience compared to other medical decisions.
- Therefore, the decision is heavily reliant on medical advice from a GP or someone who knows the child well and who has access to the latest research regarding impacts.
- Knowing the child well is important because children can have similar conditions but manifest symptoms in slightly different ways depending on age, gender, and personality of the child.
- Keeping the unit tight also narrows the range of opinions from well-meaning others – parents deliberately keep away from social media and influencers.

Preparatory conversations between children and parents have started already

- Most children have asked their parents about Covid, and as much as possible, the parents are engaging in open and honest conversations with their child to gauge the child's attitude, readiness and help anticipate any unforeseen issues.
- Many children have already accompanied their parents to their adult vaccination, or they are hearing about it at school and asking questions.
- Even if parents are not sure in their vaccination decision yet, many have started preparing their child for the physical experience. Preparations can take a long time and will require many small steps of reassurance or event practice e.g.
 - Talking about the 'tiny pin prick' and the treats to be shared afterwards

- Role playing the experience - Practice with the child pulling up their sleeve
- Wearing masks around the house to prepare for going outside
- Talking about the super-powers they will get

“I’ve already started preparing her by talking about my little army inside that tries to protect me and so I need her little army to help mine and I’ve taken her to watch me get blood off and desensitize her to needles”

- *Dyslexia, vision impairment. NZ European*

Despite starting to prepare their child, parents still have some concerns

Barriers are few but significant in size, parents have two key concerns:

1. The impact of the vaccine on the child’s condition
2. The impact of the vaccine on the child’s medication

The impact of the vaccine on the child’s condition:

- Even parents who are positive for the vaccine, worry greatly about the effect of the vaccine on their child’s condition, especially in the absence of relevant information and research-based evidence of safety.
- The thought that the vaccine could make things worse and cause more discomfort or pain for the child is unbearable.
- Some parents worry about how they will cope if their child gets an adverse reaction – in many homes’ resources are tight – getting time off work, finding someone to look after other children, dealing with the fall out is not easy.
- The decision making feels especially fraught for parents of children who are non-verbal. Having to make the decision on behalf of their child with no idea how the child may feel about this can feel very lonely for the parents.

“I am really unsure, compared with the measles vaccine it hasn’t been around that long and there’s not enough research about the long-term effects, we trusted the science enough to have the adult vaccine so I need to trust the data and I want to protect me kids as much as possible, but there’s so much unknown, so many horror stories”

- *Autism spectrum, vision impairment, inherited/genetic condition. Māori / NZ European*

Negative personal experience with the adult vaccine creates a more worrying background for some parents, especially if they share the same medical condition as the child

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- Several parents in the research had strong physical reactions to the adult vaccine, and some of these parents have the same conditions as their children. For these parents the anxiety around the vaccination decision is acute and some have been talking with specialists as to whether another vaccine type would be better.

“I have the same condition as my child, and I had a reaction. I had a heavy chest, and I was dry retching and my heart rate was high. I have a heart murmur and I felt like my chest was being crushed, the specialist has suggested another type of vaccine so it’s not a matter of if but when”

- Autism spectrum, vision impairment, inherited/genetic condition. Māori / NZ European

The impact of the vaccine on the child’s medication:

Parents will retreat at any sign of genuine risk that getting the vaccine will mean needing new medication for the child

- Fine tuning a medication regime can be a major task involving a wider team (teachers, specialists), and can be stressful for all concerned. Having to change medication to enable the vaccine to work would be a block to vaccination uptake.

“I’d be put off if I found out that the vaccine was only effective for a few months, or if I found out that the combination of the vaccine and his two medications was not going to work and we would need to consider changing this medication, that would mean some serious headaches”

- ADD, autism spectrum. NZ European

So, what information do parents need?

Parents know their children best, and they have confidence in managing their child through the experience

- Each family and child have a particular and individualised set of circumstances and needs that they manage. Parents have built extraordinary skills and confidence in working with their child and they do this 24/7.
- Other than conversations with their GP or specialist, most parents are not looking for extra help to manage their child through the vaccination decision or experience.

What parents need most is confidence, supported by research, that they are doing the right thing by their child

- For parents there is a lot to consider (and prepare) and the effort to gather information is daunting and time consuming. The more that helping agencies can proactively provide appropriate information the easier and quicker it will be for parents to make their decision.

“Even talking today, I’ve gone from ‘probably not’ to ‘probably’, because at the moment there’s no proper discussion and you think ‘am I doing the right thing’, you don’t want to think ‘should I not have done this?’”

- Depression, anxiety, spina bifida. NZ European

The information required; clear, certain and condition specific for the parents

- Overall, parents want proactive communications sent from their GP, the Ministry of Health or Medsafe - clear and certain information delivered in a caring tone that acknowledges the difficulty of the decision.
- Specifically, parents want more specific condition relevant sources of information e.g. *The risk of the vaccine on my child’s disability? The impact of catching Covid /Delta / Omicron to children with disabilities? How long do children have to stay around after the shot? How is the dose decided? What if my child is young in age but adult in size?** See appendix for full list of questions asked.

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As well as the child's GP, national disability / impairment organisations have a role to play in gathering and disseminating information

- People who are connected with condition specific established networks like Diabetes New Zealand or *Children's Autism Foundation* would appreciate proactive, specialised information, to communicate:
 - Reassurance
 - Known possible side effect and how to manage them
 - Information by age or gender where appropriate
 - i.e. some parents have two children with the same condition but it is expressed very differently in both children
 - Pros and cons of getting the vaccination
 - Impact on children with heart conditions
 - Opportunities for discussion

Fun information aids for children would also be appreciated

- For their children, parents would appreciate child friendly material like a graphic novel, or Youtube video that could be distributed through schools or sent to homes, shown on TV or made available through the Ministry of Health website, to help explain the vaccination process.

“Something that could explain it well to kids would be good, we did a lot of this with Siouxsie's glitter and soap thing, it was great, we could have a good laugh about it, you could do something about the antibodies fighting it out, anything visual would be good and it would prompt other kinds of conversations”

- *Autism spectrum, vision impairment, inherited/genetic condition. Māori / NZ European*

The ideal vaccination experience?

Some parents and children will join in local mainstream vaccination events, but most want a fully controlled environment like GP rooms

- Most parents, and especially those with children on the autism spectrum, want a calm controlled safe environment like their local GP rooms. They want certainty in medical expertise and oversight and expect a take home sheet of what to look out for and a quick response 0800 number to answer any concerns.
- One family with children who were severely disabled expected that medical staff could come to the house as taking the children out would require a lot of extra help.
- A few parents would like the schools to be involved to help normalize the experience and make life easier instead of parents having to juggle time off work, or drive elsewhere, and manage other children.

“I’d like my GP or nurse to do it, I’d feel better and so would my daughter. The first 20 minutes would be crucial, and I want to be in the right place if anything happens, I expect to just make an appointment like normal and get a take home sheet of things to look out for and maybe a follow up phone call”

- *Dyslexia, vision impairment. NZ European*

Parents want to avoid medicalising the experience – they want to celebrate it and the child’s accomplishment

- Many children are comfortable with their GP because they see them regularly, but parents would prefer that the vaccination experience does not feel medicalised – ideally, they want a low stimulation but happy, child friendly room where the child feels relaxed and not rushed – this is especially so for children on the autism spectrum.
- All parents like the idea of celebration style give aways on completion of the vaccine. Stickers, certificates, lollipops, balloons, anything that helps to keep the experience happy.
- Parents feel that this is a significant milestone to be celebrated but also, providing a happy experience is important to ensure smooth uptake of the second vaccine shot.

“Ideally I want a place not to look medical, a GP room, but kid friendly, pictures on the wall, we still need the GP rooms in case things hit the fan”

- *Autism spectrum, vision impairment, inherited/genetic condition. Māori / NZ European*

APPENDIX

*Full list of vaccine questions asked by parents

- The benefit of the vaccine
- The risk of the vaccine to children with disabilities
- One shot or two, a booster shot?
- How is the dose decided – what if my child is young in age but adult in size?
- How long do children have to stay around after the shot?
- Length of time between shots?
- General expected side effects and how to manage them?
- Can I give my child Pamol after the vaccine to lessen any pain?
- Can I bring other children along at the same time?
- Next steps?
- Where can I make appointments?
- Where can we go for the vaccination?
- Will vaccinations be needed to go to school, play sports?
- Will children get a vaccination passport?
- 0800 numbers for Q&A?
- Access to condition specific websites, organisations

“Even though I’m worried, I’m happy that the vaccine is available for children because we want to travel in summer and see a friend who is disabled and has a low immune system, it means we can see people safely and not be worried about carrying it, and some parents are stuck up and won’t let other children play if they’re sick so I don’t want them to be left out of anything, they’ve missed out on enough already”

- Depression, anxiety and spina bifida. NZ European

“At the moment I look at the sample size of the trial on children, 2,500, compared with the trial size of the adults which was 45,000 and the kids trial was recent so I’m waiting to see if there are any side effects and then I weigh up the risk of Omicron for her, I heard that covid wasn’t as life threatening for children. We will research the crap out of it before giving it to her but if Omicron blows up that will be an incentive to make the decision faster”

- *Autism spectrum (non-verbal) and postural orthostatic tachycardia syndrome. NZ European*

“I feel that this is one health decision where he is more aware than the past because the kids have been anxious about covid and they hear a lot about it at school, they are quite keen on getting the vaccine and are asking ‘why can’t I have one, I don’t want to get sick’”

- *ADD, autism spectrum. NZ European*

“There’s a lot of fear in the unknown, what happens if he’s sick or in poor health after the vaccination, who would answer for that, who would help?”

- *Cystic fibrosis, vision impairment. NZ European*

“It wouldn’t be a problem if they came to the house in a familiar environment, my son and I could manage the girls, the issue is not how it’s done, that’s not the problem”

- *Neurological disorder. Tongan*

“What will make it harder for me is if different health professionals are telling me different things”

- *Cystic fibrosis, vision impairment. NZ European*

“I want to know the effects and risk from Covid for people with POTS, what’s the risk from the vaccine and what’s are the rates of myocarditis – are these rates higher than for males in their 20’s”

- *Autism spectrum (non verbal) and postural orthostatic tachycardia syndrome. NZ European*

“He is involved with everything; we speak to him like he is an adult and support him”

- *Cystic fibrosis, vision impairment. NZ European*

“She has no voice, we owe it to her to do the best by her, to make that decision as if we were making it for ourselves”

- *Autism spectrum (non-verbal) and postural orthostatic tachycardia syndrome. NZ European*

“You want to help kids be less fearful, so I’d be fine with schools, like when we got vaccinated for tetanus, your parents signed a form. It might be easier, all in one place sort of thing”

- *Depression, anxiety and spina bifida. NZ European*