

## Town Hall Meeting Findings

### ADHS Contract: Deliverable 5

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**Summary of Findings:** In the town halls conducted it appeared that no one present had actually opted to obtain an exemption due to convenience, although an administrator felt there was a differential between kindergarten and higher level exemptions with higher grade levels being more a matter of convenience. All of those present, however, indicated that they indeed had other underlying reasons for exempting their children. The primary issues that were raised included the administration of too many vaccines at one time, the potential contaminants that were in the vaccines that might impact development and the lack of effectiveness of the vaccines. Many would prefer to space their vaccines but felt there were many logistical barriers impeding their ability to space. There were some counter-arguments from vaccinators who indicated that influential in their decision making were their personal experiences with individuals who had experienced a vaccine-preventable diseases, family members, particularly grandparents, who had witnessed child deaths from vaccine preventable diseases pushing them to vaccinate their children and conscientious and respectful clinicians who addressed their fears and encouraged vaccination. Individuals indicated they would be more comfortable vaccinating if they knew more about the vaccination development and manufacturing process and that they would like this information delivered through in-service days at the schools prior to school beginning.

### **Recommendations:**

- While in-person educational sessions are not generally possible, identifying materials from trusted sources, videos etc. and compiling these into an educational packet for school administrators to deliver in high exemption schools.
- Develop a clear and concise FAQ page about vaccines. This format of information is often very user-friendly. Include clear and concise information on vaccine spacing and the health implications of vaccination spacing, i.e. not protecting children when they are most susceptible to certain VPD etc. Links to other educational resources for questioning parents would also be useful. These should be sources that are viewed as neutral. Government or pharmaceutical websites might not be trusted. Universities with information or other research groups could be viewed as a more neutral source. Suggestions include: <http://www.chop.edu/service/parents-possessing-accessing-communicating-knowledge-about-vaccines/home.html>
- Identify key physicians who are empathetic to the parental concerns and who are willing to listen and educate them in a respectful manner. Use these clinicians to help develop and design training for other clinicians.

- Use grandmothers as good sources of information and first-hand knowledge regarding the risks of vaccine preventable diseases.
- Incorporate personal stories into informational websites of parents who have lost children or suffered consequences from not vaccinating their children.
- Incorporate education that clarifies the role that breastfeeding plays in immunity to infectious diseases.
- Most importantly ensure that communication is respectful to those who are trying to decide if they will vaccinate their children. Dismissal of fears only increases the distrust of the medical system and exacerbates the problem.

**Background and Rationale:** While closed-ended surveys can be administered more widely, holding in-depth conversations with groups and individuals can provide more subtle themes and richness to the analysis of a public health problem. To address this we set forth to conduct informal townhall meetings in schools with high exemption rates. By engaging individuals in a conversation we were able to determine themes and sub-themes that are related to choosing to vaccinate, space vaccinations or exempt children from vaccination.

**Methods:**

Recruitment Methods:

Nine schools were approached and asked if they would be willing to hold a town hall meeting with parents to discuss vaccinations and vaccination exemptions. Four schools indicated their willingness to participate.

Participants: A total of twenty-seven parents attended the town hall meetings and contributed to the discussion.

Townhall Format: An informal 10 minute presentation on vaccines and vaccine exemption was first given to provide background to the parents on the issues we wanted to discuss. Parents raised issues and concerns as a group as well as followed up with the research team after the general meeting with individual thoughts and concerns.

**Results:**

Of the twenty-seven parents in attendance 6 (21%) could be categorized as pro-vaccination, 13 (53%) would be considered anti-vaccination and 7 (26%) would be considered in the middle or neutral. Roughly 80% were females. A mix of both spacers and exemptors were present to relay their experiences with vaccination exemptions and spacing.

Several themes emerged during the discussion with relation to the individuals who chose to exempt due to convenience versus true belief in exempting against vaccines.

When first asked if people in the school might be taking them because it was somewhat easier, one for the participants said quite vehemently that it was not a matter of convenience but was other factors.

As the discussion progressed several factors emerged as recurring themes for decision making. These factors included:

**Trust:**

Trust was a factor in multiple aspects of vaccine administration. From the origination of vaccines as corporate sponsored products that generate profit. Issues were raised about the manufacturing process as well as trusting clinicians with making decisions about vaccine administration.

*"I exempt my child from vaccinations. He has not been vaccinated since 18 months old. There is a lack of trust in manufacturing of vaccinations, and administration, the rate of administration of vaccination on their little bodies. "*

*"I have a special needs child and it is separate, not related to vaccines but I do associate a lot with people who do not vaccinate. A lot of it is the trust issue....."*

Also expressed was the feeling that pharmaceutical companies were influencing the way doctors thought about administering vaccinations to the population.

*"We also don't trust the doctors. Pharmaceutical companies make a lot of money off of vaccines so of course they are going to push them. So, where are people's motives? I'm sure doctors have people's best interests at heart...they may be misinformed in some ways or... but they're young..."*

Avoidance of the issue and lack of transparency in the options that can be provided to patients by doctors and other clinicians was also cited as a problem.

*"I am a spacer, I ask for the single doses of the vaccinations because often times there are four in one vaccination and that is intimidating to me. I had a similar response, and I asked the nurse if I could get these separately and at first she lied to me and said, "no you can't" because we are on state insurance and she was not too excited about that. And I pushed her a bit and she said oh yeah that's that special batch or whatever. And just to have to push like that and have to question raises trust issues. Its just easier to do it or not do it but that middle ground where I said no I just want the individual dose and to space them out was harder work."*

It is not only in the process of obtaining information that the participants express distrust of their physician. One woman indicated that following vaccination she was worried about an adverse reaction her son had but that the doctor did not take her seriously. Naturopaths were viewed as more sympathetic to parental concerns. MD and DO were cited as perhaps more knowledgeable but....

*"brainwashed into thinking vaccines have to be administered".*

On the flip side, trusting a physician was also what led one woman to vaccinate her child. While she had questioned whether or not she should vaccinate the physician took the time to actually go over her questions and she fully vaccinated her child based upon that recommendation.

*"We chose to do vaccination because we have a very informed pediatrician. We asked about how vaccination relates to autism and he was very*

*informed and very quick to tell us "here is the deal". Most of his clients are vaccinated because he lays everything out."*

But this trust in what a medical professional says is not held by everyone. Individuals reported that they do not entirely believe that their doctor is an absolute authority or source of information.

*"I think that when parents are younger they really don't care as much and just do whatever the doctor says to do, but as I get older I start to question more and I don't blindly trust my doctor"*

**Fear:**

Fear of health problems was a big driver of both vaccinating as well as choosing not to vaccinate. The general fear of autism being linked to vaccination was remaining in the group.

*"You hear that someone got autism after having that vaccination and you become afraid."*

*"I did see two cases in which the child did develop differently after the vaccinations. Was it for sure that, I don't know but it is possible. "*

Others were fearful less of individual vaccines and more of the total number of vaccines that were administered in one clinic visit or in one shot.

*"I feel the same way. Things have changed. They are putting four diseases at once into these little bodies at one time trying to vaccinate against too many diseases at one time for a little body and I know its because they are trying to keep up. But if somebody was to get sick there are four different things and you won't know what caused it."*

Actual underlying mechanisms of how the vaccinations can cause damage were also presented. Many individuals were concerned about the number of vaccines that were given together as well as the specific components found in the vaccines, in particular the thought that large quantities of heavy metals were present in the injections.

*".....performing so many vaccinations at one time especially when there is a history of various metals being in the vaccines whether it is there to keep microbes out or to aid in the transfer of medication. I think a lot of parents are concerned about what the possibilities are for the child. Its an awful lot of heavy metals going into especially young babies when their brains are developing most rapidly."*

*"Well vaccines are made with animal proteins and the children absorb the animal proteins and they go into the respiratory tract and bypass all of the defenses and the body forms an immunity to those proteins [...] one of*

*those proteins can cause indirect problems in the brain, autism, in a roundabout sort of way."*

On the other hand individuals who had personal experience with vaccine preventable diseases or who had family that had suffered from vaccine preventable diseases were much more likely to want to vaccinate their children.

*"I grew up as a child back home in India. I had a friend who had polio and having seen a case like that I'm much more open to taking...you know, vaccinations [inaudible] because you have an example of what happened."*

Interestingly the influence of grandparents was also raised. Yet the reach was limited by the diseases that the grandparent had had experience with. Therefore the "newer" vaccines, such as flu were not as accepted as the more established vaccines that the grandparent knew.

*"Particularly in my family and the way we do it is because my grandmother was around when things weren't .... good around the diseases and she saw a lot of babies die from illnesses that could have been prevented from vaccinations and so my grandmother particularly told me that it's just like circumcising the child you have no other choice, you just do it. So she basically made sure that we got it done but we don't do any extra, we don't do flu or any of that other stuff we don't do that. We just do the particular of polio and all that other good stuff and we're done."*

But historical perspectives do not always mean that they will be pro-vaccination. Some individuals still recall participating in the chicken pox parties to get all the kids exposed at once and at younger ages and none of them remembered any negative associations with doing that.

### **Effectiveness**

Several participants felt that the risk of vaccinations was not countered by their ability to protect against disease. In fact, several indicated that they had personal experience with vaccinations not working to protect themselves or their loved ones.

*"I was given the pertussis shot RIGHT before my son was born and he was also given the shot. Even though we were vaccinated in Texas, I ended up contracting pertussis in Arizona and he did as well. It makes me wonder why we even got the vaccine in the first place if we still got sick anyway."*

*“When he was vaccinated with the flu shot, his entire arm was hard, red, and swollen. I don't want to have to worry about the reaction he may/may not have each time he is vaccinated--especially if the vaccine doesn't work.”*

These thoughts were echoed by others in one of the groups who felt that because vaccinations required boosters it made them suspicious of how effective the vaccines were in the first place.

*“Why do we need boosters? Shouldn't protection be lifelong if they are effective?”*

### **Resentment of Medical Personnel Attitude Towards Vaccine Refusal:**

Several people voiced opinions about their treatment by medical personnel when they were both questioning vaccination as well as opting to exempt their children from vaccination. Generally they felt like they were shunned, both directly by being asked to leave a practice as well as indirectly by changing attitudes of physicians and clinicians when they expressed their interest in spacing or choosing not to vaccinate.

*“Part of it too is attitudes towards doctors. I have been to a couple of doctor's offices where if you even ask questions you are told if you don't get vaccinations you will be asked to leave the practice. And so I have been asked to leave the practice because I had questions and they said read the packet and if the packet doesn't answer your questions then you need to leave the practice.”*

*“They treat you like you are a rebel force or you are one of the good people.”*

*“My younger child, he had jaundice and other things were happening, and that is when I was questioning more and I got the push-back...at the time I was very naïve and I just wanted information and it wasn't open for questioning it was just, ‘this is the law, this is the way we do it.’”*

The value of naturopath doctors as a means to better treatment and healthcare was proposed. One woman felt that the breadth and depth of knowledge was greater in the naturopathic doctors. She valued their presence in Arizona.

*“We [AZ] are also more...naturopath doctors are legal here where in New York and other places they're not, they are not even allowed to practice there so you should look at that when you do your research. Why are they not allowed to practice there? Why wouldn't they even allow it? You should look into that.”*

### **Convenience**

An administrator who attended one of the sessions felt there was a difference by age group for exemptions. In their opinion convenience was a much greater factor for older children being exempted.

*“while [parents of] younger children exempt due to personal beliefs, most 6<sup>th</sup> graders/11 year olds are exempted from boosters because parents are lazy and do not want to take day off work.....”*

### **Perceived solutions to balance fear of disease and vaccination:**

Many people felt like spacing vaccines and administering the single vaccines was a good balance for them. Quite a number expressed concerns about the spacing of the vaccines and opted to get single vaccines instead of the combination vaccines and over a greater amount of time.

*“I think it is a matter of trust as well as the spacing of vaccines. I know a lot of people who are willing to do vaccinations if they do them one at a time spaced separately.....”*

However, multiple individuals expressed logistical issues with their desire to space out vaccines. Insurance companies would not reimburse for the spaced vaccines and the lack of readily available doses of the vaccines that are not combination vaccines in the medical clinics.

Another interesting approach that was mentioned several times was the efficacy of breastfeeding to prevent infectious diseases in infants. Several mothers indicated that breastfeeding was thought to be an adequate replacement to vaccination and one went so far as to even call breastfeeding the earliest and most important vaccine.

*“And if the child is a baby, making sure those around the baby are well taken care of or that the baby is breastfed because those are the first and best vaccinations for the baby.”*

*I am an exemptor.....I just opted to do extended breastfeeding in place of that [vaccination]. “*

More knowledge was also indicated as helpful in making their decision. Several groups indicated that they would like to know more about vaccines, about how they are designed, tested and the manufacturing process that is used to generate them. Pamphlets and other paper-based information were not seen as useful. They indicated they would love to have in-person group sessions to inform and educate them more about vaccines. They preferred that these be held at prior to the beginning of the school year so they could learn about them before the vaccination deadlines for the school.

