Communicating With Parents About Autism and Vaccination: 10 Tips

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## 2009 National Immunization Survey

<table>
<thead>
<tr>
<th>For recommended childhood vaccines… (one or more doses)</th>
<th>Proportion of parents</th>
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</thead>
<tbody>
<tr>
<td>Neither delayed nor refused</td>
<td>60.2%</td>
</tr>
<tr>
<td>Only delayed</td>
<td>25.8%</td>
</tr>
<tr>
<td>Only refused</td>
<td>8.2%</td>
</tr>
<tr>
<td>Both delayed and refused</td>
<td>5.8%</td>
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Reference #1
Sources of dissatisfaction

Even with very detailed explanations, parents who feel they are not treated with respect or have unrecognized or unaddressed fears feel unhappy about the amount of information provided.
Jenny McCarthy on Rosie’s Show
Learning Objectives

• Discuss 10 tips for communicating about vaccines with parents who are unsure

• Review the C.A.S.E. method for communicating

• Highlight great tools for getting more information
Tip #1. **All it takes is perfection**

It’s hard to communicate well when you are stressed, tired, etc. The tips I’m sharing are *aspirations!*
These are my confessions:
I am not a great communicator. Many days (or parts of days) I find relationships to be a strain.
Tip #2 - Good communication starts with listening

- *Listen* with curiosity & non-judgmental attitude
- Put aside our motivation to seem smart, “be right”, “win”
- Check for what they believe now
- Hear the fear
Remember what we all want for our children:
Humiston’s 2\textsuperscript{nd} Brain Theory
AKA the Parent Brain Theory
Tip #3-One size communication does not fit all

- Mailed survey of U.S. parents in January 2001
- 90% of parents (n=1820) were classified into a of distinct parent groups:

1. **Vaccine Believer** parents who were convinced of the benefit of vaccination

2. **Cautious** parents noteworthy for a high emotional investment in their child

3. **Relaxed** parents characterized by a less involved parenting style and some skepticism about vaccines

4. **Unconvinced** parents distinguished by distrust of vaccinations and vaccination policy

Reference #3
Tip #4 - Let them know you care

- Factors predictive of effective communication between providers and patients/parents are the perception of interest, caring, warmth, and responsiveness.

- Parents’ most frequent criticisms of health care practices concern relationships with practitioners.

- These relationships have a dramatic effect on parental satisfaction, recall of instructions and treatment adherence.

- Greater trust and a better relationship with the provider have more of an effect on patient recall and satisfaction than written instructions or even the amount of time spent.

Reference #2
In the past, 1 element of doctor-parent-child communication was recognized

- **Informativeness**: quantity and quality of health info provided

Reference #2
The 3 elements of doctor-parent-child communication

- **Informativeness**: quantity and quality of health info provided

- **Interpersonal sensitivity**: affective behaviors that reflect the provider's attention to, and interest in, the parents' and child's feelings & concerns

- **Partnership building**: extent to which the provider invites parents (and child) to state their concerns, perspectives, and suggestions during the consultation

Reference #2
New 4-step Framework for Communicating Science: Making the CASE for Vaccines

- **C**orroborate: Acknowledge the parents’ concern and find some point on which you can agree. Set the tone for a respectful, successful talk.

- **A**bout Me: Describe what you have done to build your knowledge base and expertise

- **S**cience: Describe what the science says

- **E**xplain/Advise: Give your advice to patient, based on the science


Minute 14:45 to 22:30
Tip #5-Be prepared
Vaccine Concerns

See http://www.immunize.org/concerns/

Talking About Vaccines

Responding to Concerns About Vaccines

The purpose of this section is to provide medical professionals with background information and practical resources that will help them discuss immunization with concerned parents or patients. Because people question vaccination for different reasons, we have divided this section into different topics.
These videos show a provider using the CASE method in an office setting. (simulated)
Tip #6-Use English (not medicailese)
Tip #7-Use visuals
Vaccine protection from *Hemophilus influenzae* type b (Hib)

Estimated annual incidence of invasive Hib per 100,000 Children < 5 years of age, 1987-1996
Penn & Teller on Herd Immunity
(warning: 2 bad words)
Whole Brain Teaching

• Emphasis on active learning -- learner makes connections that tap both hemispheres

• Managing the emotional climate – to reduce “primal thinking” that occurs during distress

• Images are basis for comprehension
The Immunization Action Coalition's (IAC) gallery of digital images includes pictures of health professionals vaccinating children, teens, and adults; images of people affected by vaccine-preventable diseases; micrographs of viruses, bacteria, and pathology specimens; and slideshows of global immunization campaigns, past and present. Use these photos to educate staff and patients about the importance of vaccination.
Tip #8 - Use check back

Ask parents (and the child when appropriate) to repeat what they understood in their own words, and clarify info & plans.

What does the parent think?

What I say: Corroborate About my prep Science Explain/Advise
Tip #8-Use check back

2nd chance: What I meant to convey

What does the parent think I said?

What does the parent think?

What I say: Corroboreate
About my prep
Science
Explain/Advise
Tip #9 - Use reinforcers
Audiotapes

• Allows parents to:
  – Repeatedly listen to the info
  – Share accurate info w/ others who could not be present

• A study found that tapes made during outpatient visits
  – Were listened to by parents nearly universally
  – Grandparents listened to them 53% of the time
  – 70% were listened to >1 x
  – The tapes were found to be helpful >99% of the time

• Medicolegal concerns – unfounded to date
  Tapes often reveal much more info was shared than either party realized; tapes may be protective

Reference #4
Tip #10-Involve the whole office
Why involve everyone?

• If you don’t, your message may be undermined

• Champions are born when people understand the mission

• Agree on specific vaccine communication tasks for receptionist, nurse, physician

• >1 person asks for parents’ questions
Communicating With Parents About Autism and Vaccination: 10 Tips

1. All it takes is perfection 😊
2. Listen; hear the fear
3. 1 size communication does not fit all
4. Let them know you care
5. Be prepared
6. Use English (not medicaless)
7. Use visuals
8. Use check back
9. Use re-inforcers
10. Involve the whole office
A Few Great Tools
Strategies to Overcoming Barriers with Vaccine Hesitant Parents

- Understand the parent’s concerns
- Understand the parent’s influences
- Establish open, non-confrontational dialogue
- Provide unambiguous, easily understood answers
- Provide accurate info about vaccines

Reference #4
8 Provider “Competencies” for Health Care Communication

1. Develop a partnership with the patient
2. Establish or review the patient's preferences for info
3. Establish or review the patient's preferences for his or her role in decision making
4. Ascertain and respond to the patient's ideas, concerns, and expectations
5. Identify choices (including those suggested by the patient) and evaluate research in relation to the individual patient
6. Present info and assist the patient to reflect on the impact of alternate decisions with regard to his or her lifestyle and values
7. Negotiate a decision with the patient
8. Agree on an action plan & complete arrangements for follow-up

Reference #2
NGO Immunization Websites

- Allied Vaccine Group [www.vaccine.org](http://www.vaccine.org)
  - Immunization Action Coalition (IAC)
  - Vaccine Education Center of Children’s Hospital of Philadelphia (VEC of CHOP)
  - National Network for Immz. Information (NNii)
  - American Academy of Pediatrics (AAP)

- Vaccine Safety Institute [www.vaccinesafety.edu](http://www.vaccinesafety.edu)
CDC National Center for Immunization & Respiratory Diseases

• Call the hotline at 800-232-4636 (800-CDC-INFO)

• Email questions to nipinfo@cdc.gov

• See http://www.cdc.gov/vaccines/

• http://www.cdc.gov/vaccines/pubs/pinkbook/index.html
Web site for TVH is: http://www.pcibooks.com/books/view/49

• Authoritative, user-friendly guide to vaccination for healthcare workers
• Easy to navigate
• Info on:
  • Vaccine infrastructure
  • Standards and regulations
  • Business aspects of vaccine practice
  • General recommendations
  • Schedules
  • Special circumstances
  • How to address a vaccine concerns
Offit, Paul A (2008)

*Autism's False Prophets: Bad Science, Risky Medicine, & the Search for a Cure*

Columbia University Press

Profits go to autism research

See also

*Vaccines: What You Should Know* (third edition)
Beyond the Autism/Vaccine Hypothesis: What Parents Need to Know about Autism Research

It's been so rewarding to see the scientific progress being made toward understanding what causes autism and in developing better treatments for individuals with autism. While there are still a handful of parents who, in almost a religious way, cling to the notion that vaccines cause autism, the vast majority of parents and scientists have accepted what the data clearly show. There is no data to support an autism vaccine link. There never has been. Vaccines don't cause autism.

A decade ago most agreed that we need to study vaccines in relation to autism. We had to reconcile the fact that the number of vaccines children were receiving was increasing and, at the same time, the number of children who were being diagnosed with autism also was on the rise. But fortunately this was a question that could be studied - and answered - by science. We looked at children who received vaccines and those who didn't, or who received them on a different, slower schedule. There was no difference in their neurological outcomes. We've done multiple studies looking at the measles, mumps and rubella vaccination in relation to autism. We've looked at thimerosal, a mercury-based preservative, and its relation to autism. The studies are very clear; there is no relationship in the data between vaccines and autism. Read the studies themselves below.

It's Time to Ask New Questions

If we ask the same questions we'll get the same answers. We've asked the autism vaccine question over two dozen times and each time we get the same response; no relationship. We need to move on; We need to invest in studying genetics, the brain structures of children with autism, and environmental factors that may be playing a role.

Read the Science

Literature Reviews: Autism and Vaccines
References


2. Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. M. Levetown, MD, and the Committee on Bioethics. Available at http://pediatrics.aappublications.org/content/121/5/e1441.full

