



Discussing Genetics with Families



Created in collaboration with the CLG Community Health Worker Institute

Conversation Starters

“I notice you/your child has seen several specialists. Has anyone ever talked to you about a genetics referral?”

“Have you ever told your doctors that there are several people in your family with the same symptoms as you?”

“Other families in your situation have found that an appointment with genetics can be helpful.”

Topics to Avoid

Providing recommendations

Discussing how you would handle their situation

Making a prognosis about a child’s condition

Answering medical questions about genetics

Sharing too much personal information about your lived experience

If any of these topics come up, here’s one way to respond...

“This sounds like a good question for your health care provider. I can help you make a list of all of your concerns that you can bring to your next appointment to discuss with them.”

The objective of the genetics training is to help CHWs identify families who could benefit from genetic services, provide support and offer advice on how to discuss genetics with their primary healthcare provider. A CHW should never try to make a genetic diagnosis or provide any medical advice about genetics.



For additional resources on frequently asked questions about genetics services, please visit nymacgenetics.org/new-jersey.

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Genetic Conversations Do's and Dont's



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Don't say "Your child is autistic."



Do say "Your child has a diagnosis of autism spectrum disorder."

Always remember to use person first language!



Don't say "A genetic specialist can help to determine if your child has a genetic mutation that is causing their issues."



Do say "A genetic specialist can help to determine if your child has a genetic variation that may be the cause of their health issues."

The word "mutation" is perceived very negatively. The words "variation" or "change" are more neutral. Not all genetic variations/changes are harmful. Some cause no effects, and some can be actually helpful to the individual.



Don't say "Your child has autism. It could be genetic."



Do say "I learned that often, autism can be caused by a genetic change. If this is true for your child, it could impact other children or family members. Did you know that children diagnosed with autism should ALL be offered a referral for a genetics appointment? If you are interested, we can talk about how to start that conversation with your child's pediatrician."

Determining whether autism is due to genetic changes is complex and requires specialized genetics tests, which can only be ordered by a healthcare provider.



Don't say "Your child has a lot of health issues. It's probably due to a genetic change."



Do say "I noticed your child has a lot of health challenges. Sometimes children with multiple health challenges have a genetic change that causes their health issues. This is something you could discuss with your child's pediatrician to see if a genetics referral might be helpful for your family."

Making a genetic diagnosis can only be done after careful examination and testing by a healthcare provider with expertise in genetics. A CHW should not suggest any specific genetic conditions or attempt to make any genetic diagnoses. Instead, offer support and direct the family to discuss genetics with their child's pediatrician.

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