Developmental Behavioral Topics

- Do I need to see a doctor/specialist with expertise in 22q11.2DS?
Resources-Medical

- Medical surveillance
  - EKG, echocardiogram, renal ultrasound, etc.
  - Swillen 2011

- Other conditions:
  - Fatigue
  - Nosebleeds
  - Sleep problems
  - Recurrent infections
  - Growth
Developmental Behavioral Topics

- Do I need to see a doctor/specialist with expertise in 22q11.2DS?
- How and when do I tell my child s/he has 22q11.2DS?
Developmental Behavioral Topics

- Do I need to see a doctor/specialist with expertise in 22q11.2DS?
- How and when do I tell my child s/he has 22q11.2DS?
- Unidentified anxiety can manifest in different ways
  - Avoidance/withdrawal
  - Oppositional behaviors/ODD
  - Inattention
  - Somatization
  - Repetitive questioning
Developmental Behavioral Topics

- Do I need to see a doctor/specialist with expertise in 22q11.2DS?
- How and when do I tell my child s/he has 22q11.2DS?
- Unidentified anxiety can manifest in different ways
- Autism symptoms and social competency
  - Reported in up to 50% in the literature but this not based on gold-standard assessments
  - Socially motivated, but poor social skills due to developmental delay, language difficulties, concrete thinking, and/or anxiety
  - What is the most appropriate treatment?
Developmental Behavioral Topics

- Do I need to see a doctor/specialist with expertise in 22q11.2DS?
- How and when do I tell my child s/he has 22q11.2DS?
- Unidentified anxiety can manifest in different ways
- Autism symptoms and social competency
- Setting appropriate expectations
Take home points

• You know your child best so partner with your provider in creating a plan
  – Respect the provider’s expertise, but also realize that you can contribute by providing resources and educating your provider

• Rather than focusing on a label or diagnosis, try to figure out WHY a behavior is occurring and what changes can be made to improve the situation