

Concepts of Personal Boundaries, Respect and Consent

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Personal Boundaries

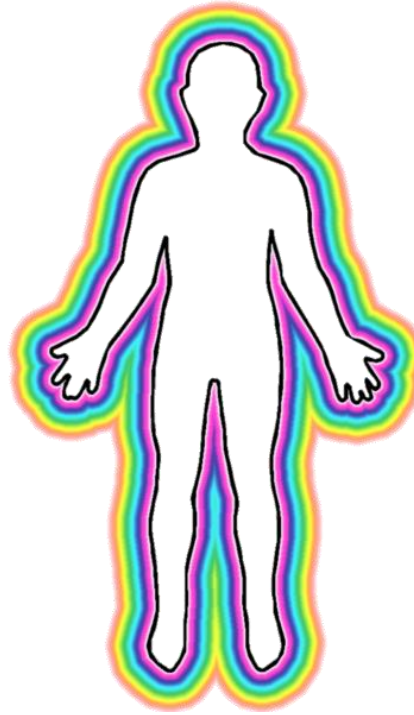
- * Important to **teach** all children to have a clear, strong voice in regards to their **rights** (at an early age):
 - Confidence** to speak up when they are unhappy or feel uncomfortable in any situation
 - Strength** to ask for support, when needed
 - Knowledge** to know when to say no or ask for help

Personal Boundaries

Social/
Emotional

Physical,
Sexual

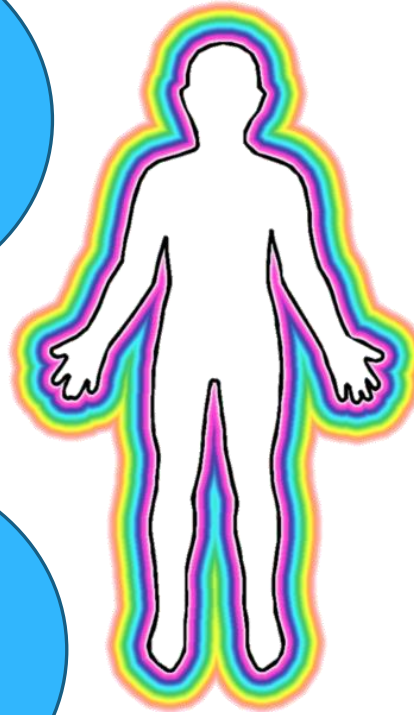
Digital



Personal Boundaries – vulnerabilities in adults with 22q11.2DS

- Delayed social maturity
- Poor insight, judgment
- Social skills deficits

**Social/
Emotional**



- Relative strengths in computer based skills

Digital

- Multiple medical conditions
- Generally no fertility issues

**Physical,
Sexual**



Respect

- * What does respect look/feel like?
 - * Trusting
 - * Feeling SAFE and comfortable
 - * Not having to worry about any type of harm (physical or emotional)
 - * Supportive, mutual relationship

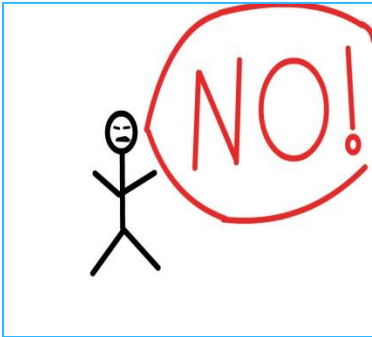
During transition to adulthood – increased need for positive social supports

Consent

- * Agreeing to something, giving permission or saying “yes”
- * MUST BE:
- * Voluntary – without coercion
- * Feeling comfortable and willing
- * Having awareness and understanding of the situation
- **knowledge of risks and consequences**

Consent

**IT IS ALWAYS OKAY TO SAY NO
SAY IT:**



Out loud



Gesture

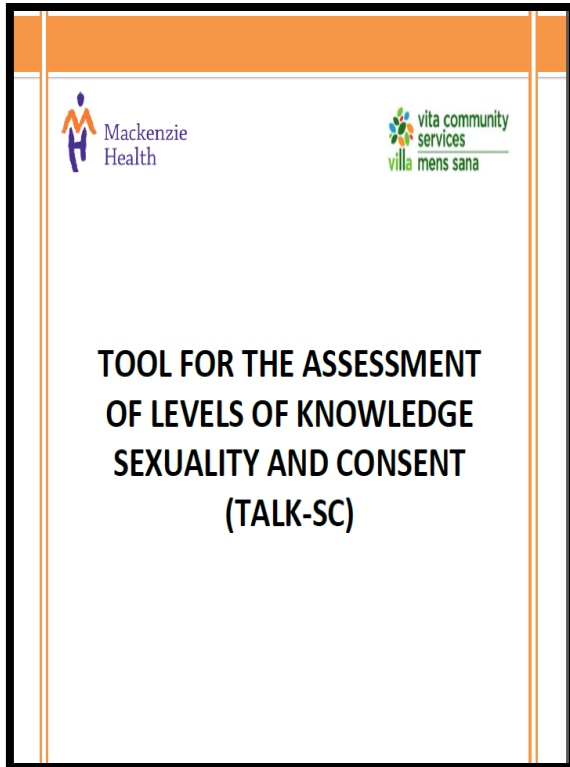


Walk away

Consent

- * Capacity to make informed decisions
 - * Age (not mental age)
 - * Personal care, financial – capacity assessments
 - * Sexual – no formal measure
- Knowledge is power**
 - * Awareness and understanding of basic concepts including potential risks and consequences
 - * lack of knowledge can indicate lack of ability to make informed decisions

TALK-SC



1. Understanding of public and private places, topics and body parts
 2. Nature of sexuality and the right to say yes or no
 3. Pregnancy and choice
 4. Sexually transmitted infections
 5. Sexual acts that are against the law and possible problems in relationships
- * **Structured clinical questionnaire**
 - * Genetics, standard technology, sexual history

Preliminary Results

Overall level of knowledge – TALK-SC

Most “fails”

29 (67%) of 43 adults
"Failed" 1 or more of
the 5 sections

Nature of sexuality and the right to say yes
or no

Sexually transmitted infections (STIs)

Sexual acts that are against the law and
possible problems in relationships

Understanding of public and private places,
topics and body parts

Pregnancy and choice

Least “fails”

Some Tips:

- * Reminders, repeated education
- * Simple, concrete examples
- * Visuals
- * Ask direct questions to clarify understanding
- * Supervise, monitor, as appropriate
- * Give one or two choices – practice weighing pros and consequences of each choice
- * Ask for support, as needed

Thank you!



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