Independent Living Skills for Individuals with X and Y chromosome variations

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Disclosures: None
Independent Living

Is my child ready?
Independent Living Skills

- Staying Healthy
- Day – to - Day Living things
- Keeping it Safe
- Social Skills
- Social Connections
- Day- to - Day Financial management
How to Support Decision Making and Learning: Path to Independence

Realistic Goals
Child’s Interests and Abilities
Environment and Resources
Staying Healthy: Medications

Things to know about meds:
• Why you need to take them?
• What happens if you missed doses?
• Adverse effects
• Who prescribes them?
Staying Healthy: Medications

How to take them independently
Staying Healthy: Medications

How to take them independently
Staying Healthy: Medications

How to manage refills
Staying Healthy

Keeping up with doctor’s appointments
Day- to - Day Living things

Cooking
Personal Hygiene & Laundry
Driving & Transportation
Keeping it Safe

Food safety
Personal safety
  cell phone GPS locator, landlines, when to call 911
Internet Safety
  Netnanny
How to interact with police
Social Skills
Finding and keeping a job
• Identifying personal interests & abilities
• Interviewing
• Asking for accommodations
• Keeping a schedule
• Staying on task
Social Connections

Bulling & Self-Advocacy
Disclosure
Sexuality & dating
Disclosure- Telling Others

• School/ Work
  Advocacy for Resources & Accommodation
  Misconception as lazy

• Family & Friends
  Right to privacy
  Misinformation by internet & social media

• Dates
Disclosure

What we know from research on other genetic conditions

Challenges: Whether, when, what and how to tell

Concerns: fear of rejection
  too soon or too late
  how much detail to disclose

What may influence decision to disclose:
  individual and family attitudes and beliefs
  getting to know other families may help

Strategies: open vs. selective
Disclosure-How to tell

• In person- no text or emails
• Make a plan according to circumstances
• Be truthful & keep a positive attitude
• Framed in the context of the individual (not what is written in textbooks or internet)
• Use simple terms and direct language
Thank you!

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Klinefelter and other XY Variations Program