

# Being Prepared for Adulthood with Fragile X Syndrome

Presented by

H. Laurie Yankowitz, Ed.D. and Vicki Sudhalter, Ph.D.

**A Practical Introduction to Increasing Independence and  
Accessing Supports and Services for Adults**

NATIONAL FRAGILE X CONFERENCE

Orange County, CA

July, 2014

We Come To You in Peace from Your  
Child's Future and

The

Adult

Service

World





*On a mission  
to help you prepare YOUR loved one  
for ADULTHOOD with Fragile X*

*BECAUSE people with Fragile X and their families  
are some of the BEST people we know  
(and that's the truth)*

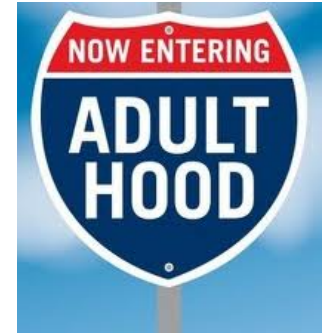




# *TODAY'S PRESENTATION WILL COVER:*

- I. Mission and purpose of services for adults with developmental disabilities: snapshot of national and state policies that reflect current thinking on service goals and quality of life for adults with developmental disabilities
- II. Increasing independence at home and in the community
- III. Becoming familiar with the adult service world in your state – and the importance of getting your feet wet while transitioning from school to adult
- IV. Maximizing transition planning in the IEP – focus on practical life and vocational skills
- V. Identify and explore future planning needs:  
-- legal guardianship    --special needs trust

# Adulthood



Comes with  
privileges and responsibilities

The United States considers adults with  
developmental disabilities to have the rights and  
responsibilities of full-fledged citizens at the age  
of majority

*unless determined otherwise in a court of law*

# Federal Requirements for Services for People with Developmental Disabilities

- The interdisciplinary team must prepare an Individualized Program Plan **which includes opportunities for individual choice and self-management** and identifies: the discrete, measurable, criteria-based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports, and techniques to be employed. **The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible**, and the prevention or deceleration of regression or loss of current optimal functional status.
- (42 CFR 483.440(c))

Focus of Services and Supports  
for Adults with Developmental Disabilities:  
U.S.A.'s National Core Indicators



NCI identifies desired outcomes for services provided by agencies supporting people with developmental disabilities.

You have a handout that provides an overview of the domains state governments are expected to monitor. They are:

- [Individual Outcomes](#)
- [Health, Welfare, and Rights](#)
- [System Performance](#)
- [Staff Stability](#)
- [Family Indicators](#)

# Individual Outcomes

(see hand-out)

- Individual outcome indicators address how well the public system aids adults with developmental *disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination.*
- Other indicators in this domain probe how satisfied individuals are with services and supports.
- **Sub-domains:**
  - Relationships
  - Satisfaction
  - Self-Determination
  - Choice and Decision-Making
  - Community Inclusion
  - Work



# The Work of Adulthood



- The achievement of these individual outcomes is the work of adulthood.
- Supporting the achievement of these individual outcomes is the foundation of today's adult service world.
- The supports provided to help achieve these outcomes is called (in most states) **habilitation services**.

# The business of adult services is HABILITATION

Miriam Webster: habilitation is the process of supplying a person with the means to develop maximum independence in activities of daily living through training or treatment.

SCHOOLS educate *children*  
AGENCIES habilitate ADULTS

(day habilitation; residential habilitation;  
community habilitation; vocational habilitation)

# Teens and Young Adults w/ FXS and Maximizing Independence

## STRENGTHS AND CHALLENGES

Teens and young adults w/ FXS *typically*...

- **LIKE being independent** – they are highly motivated to do things for and by themselves
- **EXCEL at self-care routines** and enjoy helping others
- **Take pride in their accomplishments**
- **Respond positively to purposeful activity**
- WANT to get tasks DONE, and ***quickly***
- **Can become easily frustrated** when not successful
- **Are very sensitive to distractions** in the environment
- **Can be overwhelmed** by lots of direct verbal instruction
- **Are prone to having their capabilities underestimated**

# Strategies for Maximizing Potential for Independence

- Acknowledge and praise accomplishments *and* efforts in context of helpfulness or intent to be helpful (but avoid gratuitousness)
- Teach by showing (vs. telling)
- Sandwich new learning between mastered steps or tasks
- Start with the end result and work backwards
- Practice new skills in purposeful contexts
- Frequent BRIEF learning sessions
- Use checklists and timers
- Minimize distractions (e.g. headphones, sunglasses)
- Employ S-I strategies to calm hyperarousal

# Promoting and Supporting Independence for Adults with FXS

SHARE THE 2 PREVIOUS SLIDES WITH  
SERVICE PROVIDERS!



# INDEPENDENCE AT HOME

(see handout #2: Adolescent autonomy checklist)



Cooking



\*Laundry



Changing a light bulb

# INDEPENDENCE AT HOME



vacuum



Wash windows



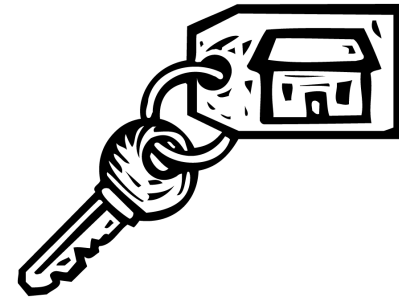
sweep



REGULATE water  
temperature  
(= privacy)



Take out the trash



Use keys to the house

# Independence in the Community

Making appointments:

haircut



doctor



social visits





# Tools for Making Appointments

Sun	Mon	Tue	Wed	Thu	Fri	Sat



# Choice-making for individuals with very limited verbal expression

- On Saturday (point to calendar), show me who you want to visit (put out photos of friends and family – add velcro to back so individual can place photo on calendar (don't underestimate how empowering this might be))
- Explore communication app demos at [www.a4cwsn.com](http://www.a4cwsn.com)
- Support participation in supermarket shopping by making a visual shopping list and be sure individual is given options of preferred items to include

# Independence in the Community

Cell phone =  
freedom

\*use photo and  
email to identify  
location

\*use of 911



smart phones now  
show photos of  
people with their  
phone numbers and  
will dial with one  
touch)

Give  
responsibility  
for charging  
all the devices  
in your  
household?

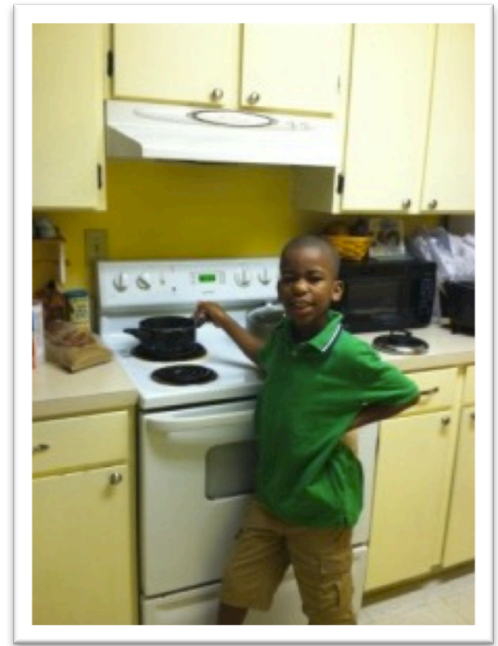
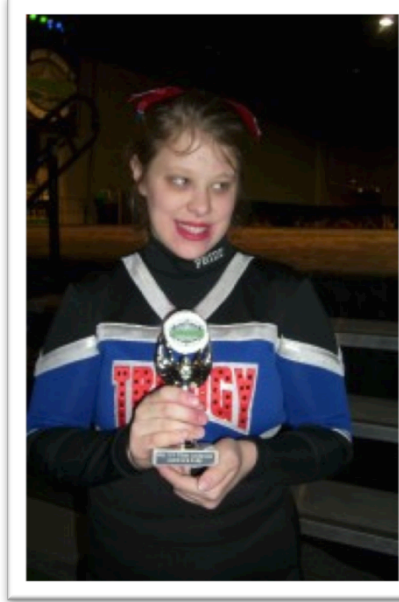
# Independence in the Community



Ability to use public transportation =  
\*dignity      \*work opportunities      \*freedom for the entire family

# Need inspiration?

- Read real-life stories of the accomplishments of individuals with FXS: [www.fragilex.org](http://www.fragilex.org) -  
Keyword “Faces of Fragile X”



ARE YOU PREPARED (TO)



Promote, ENCOURAGE, support, SCAFFOLD, allow,  
*cheer, further, develop*, PUSH,  
CHAMPION, nurture, and empower  
increasing independence?

# Teaching Independent Living Skills: When? Who? How?

- Use teachable moments throughout your morning, evening and weekend routines – add a few extra minutes to teach or allow learning from mistakes vs. “doing for”
- Set up a schedule for in-home and community support services

# Could you use some help?

## Community Habilitation

- A service available in many states to teach independent living skills at home and in the community
- Find your state agency responsible for DD services at <http://www.nasdds.org/state-agencies/>
- Keyword “home and community waiver services” on the website or call and ask for information about in-home services



# Accessing Publicly Funded Supports and Services

- Most services are funded by **Medicaid** and accessed through enrollment in the “**Home and Community Based Waiver Services**” (also known as “the Waiver”)
- Parental income is *waived* for Medicaid eligibility for children and not a consideration for adults; regulations that prohibit Medicaid for paying for certain services are *waived* for special populations

# Medicaid and Adult Services

- Eligibility and enrollment requirements vary state to state – find out yours, starting with the state agency (and have a notebook handy, to document who you spoke with, the date, who you were referred to, and their phone number – again and again and again)
- <http://www.nasdds.org/state-agencies/>  
(use this link to find YOUR state agency)

# Adult Services

*Not* mandated and are *not* entitlements

Unlike special education, services for adults with development disabilities ARE NOT entitlements under the law—you need to be highly pro-active to obtain them

Agencies *voluntarily* provide services; if funded by public funds, these services ARE regulated by federal, state, and sometimes local government authorities.

Most states have a due diligence process to appeal denial of services for eligibility, acceptance and discharge.

# Eligibility Requirements in California

- **Eligibility Requirements**
- Must have eligibility for full scope Medi-Cal
- Must have a formal diagnosis of a developmental disability that originates before an individual attains the age of 18, as defined in the California Lanterman Developmental Disabilities Services Act, Welfare and Institutions Code, Section 4512(a)
- Must be a Regional Center consumer
- Must meet the level of care of the Federal intermediate care facility for the mentally retarded (ICF/MR), or in California, the ICF/DD-type facilities

# Waiver Services Provided in California

- Homemaker
- Home Health Aide Services
- Respite Care
- Habilitation:
- Residential habilitation for children services
- Day habilitation
- Prevocational services
- Supported employment services
- Environmental Accessibility Adaptations
- Skilled Nursing
- Transportation
- Specialized Medical Equipment / Supplies
- Chore Services
- Personal Emergency Response System (PERS)

# Waiver Services Provided in California

- Family Training
- Adult Residential Care:
- Adult Foster Care
- Assisted Living
- [Supported Living Services](#)
- Vehicle Adaptations
- Communication Aides
- Crisis Intervention:
- Crisis Intervention Facility Services
- Mobile Crisis Intervention
- Nutritional Consultation
- Behavior Intervention Services
- Specialized Therapeutic Services
- Transition / Set-Up Expenses
- [Habilitation](#)



# Respite

- Good for YOU *AND* good for them!
  - *Your adult child is grown up but still requires more care and attention than typically developing peers – you deserve some respite!*
  - *This service is a great way to dip your toes into the adult service system, and provide both you and your family member with bite-sized doses of new relationships with paid staff and their employers*
  - *Let some younger people run around with your young adult while you take it just a bit easier*

# Respite



Many types:

In-home and in the community

Day Respite: Evenings and weekends; individual and group recreation

Overnight Respite: Planned and Emergency; weekends or weeks at a time

Freestanding Respite/"Hotel" Respite/ "Travel" Respite  
(AHRC; UCP; Sprout; HeartShare)



# Back to School: Make the Most of IEP Transition Plans

**By age 16, IEP must include:**

**\* Goals to work toward competence in 3 areas:**

--**Personal and social skills**

to promote community participation and interpersonal relationships

--**Daily living skills**

to maximize independent self-care

--**Occupational and vocational skills**

to prepare for work

~BEGIN WITH THE END IN MIND~



# RESOURCES for TRANSITION PLANNING

Recommended for families of individuals still in school as well as those who have already aged out, no matter what state you reside in – the information, values and approach are relevant and very comprehensive overview of the transition planning process:

[http://www.isbe.net/spec-ed/html/transition\\_video.htm](http://www.isbe.net/spec-ed/html/transition_video.htm)

Produced by the Illinois State Board of Education  
*TOTAL PROJECT (Transition Outreach Training for Adult Living)*

And for an excellent tool for person centered planning:

[http://www.isbe.net/spec-ed/pdfs/TOTAL\\_module2\\_resources.pdf](http://www.isbe.net/spec-ed/pdfs/TOTAL_module2_resources.pdf)

includes a checklist to identify learning style, what kind of job he might like, hobbies and preferred activities, -- will be helpful not only for the IEP but for after school when accessing adult services

# NFXF Adolescent and Adult Project

Great information is available at

[www.fragilex.org](http://www.fragilex.org)

key word: Adolescent and Adult Project

Includes videos vignettes demonstrating supports to talk on the phone, walk to work, and deal with anxiety.

Also see:

<http://www.fragilex.org/2013/treatment-and-intervention/8-tips-on-transitioning-your-child-to-adult-services/>

# Future Planning Needs



Learn about:  
**LEGAL GUARDIANSHIP**  
and  
**SPECIAL NEEDS TRUSTS**





# Guardianship

- Legal guardianship is especially important when considering residential alternatives (to living with you) and medical decisions.
- Remember that the law treats your child as an independent citizen when they reach the age of majority until and unless the court has awarded guardianship

# Special Needs Trust



- If you plan to leave an inheritance, it is **ESSENTIAL** that you hire an attorney with experience in special needs trusts to insure that your family member will be able to continue to receive public benefits and be able to use their inheritance for life enrichment as opposed to meeting basic needs.



ALL PREPARED NOW?? 



QUESTIONS???