

Expanding Social Opportunities for Young Adults

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Overview

- Identifying the problem
- Expanding social opportunities for adults
 - Child vs. adult considerations
 - Identifying what is important to adults and their families
- Programs at UCSF STAR
- Discussion

A public health crisis

- ~50,000 adolescents with ASD turn 18 each year
 - Expected 123% increase in youth exiting high school in the next 10 years

- Research highlights challenges for adults
 - High rates of unemployment and underemployment
 - Difficulty with daily living skills and achieving independence
 - Elevated rates of physical and mental health problems
 - Limited access to services
 - Few social contracts or relationships

LACC, 2017

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WHY?

LACC, 2017

This is a large-scale, systemic problem!

Challenge	What impedes achievement
High rates of unemployment and underemployment	Insufficient availability of jobs
Difficulty with daily living skills and achieving independence	Limited focus on learning life skills
Elevated rates of physical and mental health problems	Lack of appropriate preventative care
Limited access to services	Difficulty navigating the system
Few social contacts or relationships	Loss of activities and routines

How can we make a difference at an individual or community level



How can we make a difference at an individual
or community level

*Adult-focused social
interventions*



Adults are not just older, larger versions of children!

- **Adult social interactions are more complicated than child interactions for everyone**
- **Avoid applying child programs to adults due to developmental differences in:**
 1. Environments
 2. Types of relationships
 3. Social rules
 4. Social expectations
 5. Motivation for seeking social opportunities

Differences in environment

- **Children and teens interact in adult-controlled environments**
 - School; extra curricular activities
- **Adults interact in environments that are fluid and can be unpredictable**
 - Professional (employment; volunteer organization; college classroom)
 - Community (restaurants; bars; sporting events; gym; theater; park)
 - Organized events (parties; exercise class; art gallery)
 - Private events (family get together; celebrations; dates)

Differences in types of relationships

▪ Children and teens have fewer different types of relationships

- Peers (classmates; teammates; friends)
- Authority figures (teachers; parents)

▪ Adults have a variety of different relationships

- Professional (employer; supervisor; co-worker)
- Community (sharing a Lyft; sitting next to each other in the theater)
- Casual (acquaintances; classmates; sexual partners)
- Personal (family; significant others; friends)
- Other (roommates)

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*****Not always
mutually exclusive*****

Differences in social rules

- **For children and adolescents, rules vary more predictably by environment**
 - Classroom vs. playground behavior
 - Known vs. unknown
 - Peers vs. adults
- **For adults, social rules depend upon multiple factors**
 - Environment (where you are, who else is around)
 - Type of relationship (boss vs. friend)
 - How well known the other person is
 - level of intimacy, length of relationship vs. frequency of contact!

Differences in social expectations

- **Children and adolescents are learning to navigate the social world**
 - More forgiving of unusual behavior or faux pas (especially with younger children)
 - Behavior often ascribed to developmental stage or temporary state (e.g., “he’s just a kid” or “she’s just a moody teen”)
- **Adults should know the social rules and “read” nuances of the situation**
 - Adults should adjust behavior in real-time according to the situation
 - Nonverbal cues (e.g., looking at watch; changing subject; length of eye contact)
 - Awareness of changing context (e.g., start of activity; others join)
 - Behavior often ascribed to the adult’s character (e.g., “he’s a jerk”; “she’s weird”)

Differences in motivation to socialize

- **For children, motivation is often to “fit in”**
- **Adults may have many different motivations**
 - “Fitting in” to specific groups (e.g., at work)
 - Being engaged in their community
 - Sharing interests; Support and advocacy; Contributing to society
 - Finding/maintaining a job
 - Developing/maintaining relationships
 - Finding a significant other or “best friend”; Sexual relationships; Roommates
 - Self-competence/feeling connected (not lonely when alone; Facebook phenomenon)

Other considerations

▪ Availability of opportunities

- School is a required part of child's daily routine; fewer extracurricular choices
- Not all adults are employed or in school; participation in “extracurriculars” is adult-motivated and based on both individual and common interests

▪ Others' expectations and understanding of ASD

- Some school programs promote understanding; community understanding varies

▪ Safety

- Personal and others (e.g., being taken advantage of; cues being misread)
- Law

Where do we start?



Where do we start?



Identify a focus!

Avoid assumption that all adults want the same things

- **Research suggests >50% adults with ASD have “poor” or “very poor” outcomes (Magiati; 2014)**

- Dependent on parents or caregivers
- Requiring significant support for education and employment
- Often socially isolated; few friendships or romantic relationships

- **Definitions too narrow or ignore personal preferences**

- “Successful transition” more nuanced (Henninger & Taylor, 2014)
 - 65%: Occupation \neq full-time paid employment
 - 44%: Moving out apart from parents \neq 100% independence
 - 26%: Relationships with peers vs. 9%: Romantic relationships

Getting perspectives of adults and their families

- Goals:

- Identify areas that adults are motivated to focus on RIGHT NOW
 - In what environments are they struggling?
 - What kind of interactions are most difficult?
 - What frustrates or confuses them?

- Focus groups

- Research Surveys

Socialization at work

- *Quotes were omitted to protect patient privacy; topics were summarized*
 - Socialization interactions on the job
 - What is to appropriate to talk about and how to set boundaries at work
 - Miscommunication and misunderstandings at the workplace
 - Being reprimanded or receiving feedback
 - Concerned being labeled at incompetent
 - Social anxiety

Friendship

- *Quotes were omitted to protect patient privacy; topics were summarized*
 - Understanding deepening friendships and relationships
 - Fear of opening-up and being vulnerable
 - Feeling behind other peers in development

Dating/ Sex/ Intimacy

- **Quotes omitted to protect patient privacy; individuals highlighted**
 - Comparing relationships to others around them
 - Questions about intimacy
 - Disclosure
 - Issues with past trauma
 - Boundaries

Parent perspectives

*What would you consider to be a meaningful achievement or "outcome" for your son/daughter?
In other words, what do you hope for him/her to achieve to be happy and content with life?*



**Live in a community that
cares/understands;
Be around family/friends**



**Be healthy/
physically active**



**Increase
independence
in daily
activities**



**Find happiness
and enjoyment**



**Make meaningful
contributions**

Intervention targets based upon data

Challenge	Targets for social interventions
High rates of unemployment and underemployment	Job interviews; disclosure; communication with co-workers;
Difficulty with daily living skills and achieving independence	Specific skills; lack of trained (para)professionals to provide support
Elevated rates of physical and mental health problems	How to maintain physical/mental health; coping strategies
Limited access to services	Advocacy skills
Few social contacts or relationships	How to develop and maintain friendships; communication; intimacy/boundaries

Next steps to developing programs

- **Skill-based in the clinic vs. experiences in the community**
 - Not everything can be taught using didactics
- **Who is the target audience?**
 - Age, gender, IQ, language, etc
 - Same topics may require different lessons or approaches for different groups
- **What programs already exist?**
 - Can it be used “as is”?
 - Are there elements from different programs that can be combined?
- **If no program exists, what research exists to guide development?**

Take Home Observations for parents and providers

- **There is a need for programs that target skill development, as well as those that provide social opportunities for adults with ASD**
 - One size does not fit all: Needs may vary by age, gender, ability, etc.
- **Programs need to be designed with ADULTS in mind**
 - Young adults with ASD want to do age-appropriate things (socialize, have fun, have relationships, date)
 - They want to be included in activities in the community, not just events for those on the spectrum.
 - Adults with ASD are often aware and self-conscious of their challenges; it can be helpful to normalize difficulties that everyone faces

Groups

- One group can't do it all – leave room to address complexity and nuances
- Needs of the group will be continual and changing
- Need to be in several environments, including community based learning experiences
 - Skills need to be practiced outside of the program

STAR Center for ASD & NDDs

Programs for Adults with ASD
Seeking to Enhance Social Skills &
Expand Social Opportunities

STAR adult social opportunities

- Different programs to meet different needs
 - Structured skill development groups (e.g., PEERS)
 - Semi-structured special topic seminars (e.g., Women's group)
 - Unstructured experiences (e.g., Community meet-ups)
- Eligibility (varies by group)
 - Age, language/cognitive ability
 - Motivation to participate

Deciding fit

■ Assessment goes beyond diagnosis

- IQ
- Language level
- Comorbid psychopathology
- Adaptive functioning
- Motivation for seeking services/type of service they are seeking; for example:
 - Do they want to be taught skills (didactics) or simply increase social opportunities?
 - If employment is a focus, what are their skills and preferences?
- Currently available social opportunities

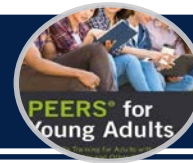
■ Mixed diagnosis or ability groups may be appropriate depending on group focus

Parent Assisted Social Skills Group: PEERS® Program

Developed by Elizabeth Laugeson, PsyD at UCLA
Evidenced-Based Social Skills Program

- Target age: 18 – 35
- Caregiver involvement: Concurrent Parent and Young Adult group
- Focus: skills for friendship/dating
- Duration: 16 weeks
- Next group: January 2018- currently recruiting

PEERS® Young Adults



Parent Assisted Social Skills Group: PEERS® Program

Rules and Steps of social behavior are developed from research:

1. Common social errors often committed by those with ASD
2. Core skills needed to make and keep friends and develop
3. Ways socially accepted individuals handle per conflict and rejection

Lessons focus on friendship and dating

- starting maintaining conversations, finding a source of friends
- using electronic forms of communication
- using humor appropriately
- organizing successful get-togethers
- learning dating etiquette
- managing disagreements
- handling direct and indirect bullying and other forms of rejection

Parent Assisted Social Skills Group: PEERS® Program

- Group Format
 - Didactic, perspective taking questions, role plays/video models, practice with feedback
 - Weekly HW
- Social Supports
 - Social Coaches
 - Behavior Coaches
- Participants: Include YAs without ASD
- Intake Process
 - eligibility criteria: verbal ability and social motivation

PEERS YA: Satisfaction surveys- *What did you learn or find helpful?*

■ Parent

- “This group and support makes it so much earlier to introduce and reinforce the skills to my YA.”
- “Have learned to be a better support for my son. I like the format for coaches.”

■ YA

- “I have learned how to enter a group conversation and introduce myself. I also learned how to apply humor.”
- “Social Skills can be learned. The importance of knowing how to ask questions.”

Women's Group

Developed by Tara Glavin, BCBA

- Target Age: 18 – 39 year old
- Caregiver involvement: not included
- Focus: social support; skill-focused modules vary
- Duration: 8 weeks
- Next group: February 2018 - currently recruiting

Women's Group



Women's Group: Topics and goals

- Topics developed by group: After the initial group members ranked ordered topics:
 - Dating/ sex and intimacy, employment, friendships, money , physical health and transitions
- Group 1: Employment (completed)
- Group 2: Friendships
- Women's Group Goals
 - Share experiences
 - Give and receive support from peers
 - Learn about maintaining close or intimate relationships
 - Problem solve current social challenges in their lives
 - Provide tools to handle disagreements

Women's Group: Employment and skills

- Employment experiences vs. school experiences
- Healthy boundaries at work
 - Social and work responsibilities
- Social interactions with coworkers
- How to highlight your skill sets
- Leadership
 - Participants weekly took a leadership role; they chose/created their own topic and during the first week
- Communication
- Routines

Women's Group: Satisfaction surveys – *What helpful things have you learned?*

- “Compassion for other women, that are in different stages of life.”
- “That I am not alone when it comes to being a women and having autism.”
- “I enjoyed listening to others discuss situations and questions that I’ve also had that correlate to my disability.”
- “There is so much about this group; it’s overwhelming to list the items.”
 - “Self-confidence, my boundaries and advice.”

Community Meet-Ups for Young Adults

Developed by Tara Glavin, BCBA

- Target age: 18+
- Caregiver involvement: not included
- Focus: maintenance of learned skills in community setting
- Duration: ongoing
- Next Meet-up: Mid-December

Community Meet-ups



Community Meet-Ups for Young Adults with ASD

- Goal: Maintenance of social skills in informal, community settings
- Participation: Previously received STAR Center services
- YA take leadership in planning (typically restaurant of their choice for dinner)
- STAR staff attend get-togethers with YA to facilitate social interaction
- Occur monthly
- Cost: YA pay for their own food/drink

What do we do and where do we meet?

- YA choose where we go
 - Different neighborhoods, Accessible by public transportation
- Diverse environments; Burger place, Japantown, Russian food
- Relaxed social setting. STAR staff attend to encourage socializations and conversation skills.
- Young adults have made plans with each other outside of the group.
- In-situ-coaching

Transitioning Together

Developed by Leann Smith, PhD, at University of Wisconsin-Madison
Evidenced-Based Program

- Target Age: 14 – 21 years
- Caregiver involvement: Concurrent Parent+Teen/YA Grp
- Duration: 10 weeks
- Next group: TBD 2018

Transitioning Together



Transitioning Together

▪ Goals:

- reduce family distress
- improve family problem-solving
- support social engagement and self-direction of transition-age individuals with ASD

▪ Topics covered in parent sessions:

- Autism in adulthood, employment planning , college planning, problem-solving , family topics, risks to adult independence, community involvement, legal issues, health and wellbeing

▪ Topics covered in teen/YA sessions:

- Goal setting, social problem-solving, coping strategies, conversation skills, party planning/graduation
- Flex week built-in to curriculum so teens/YA can choose a relevant topic of their choice.

Details/How to enroll in a group

▪ Insurance-based services/self-pay services (outpatient)

- It is complicated our clinic coordinator will talk to you about your situation

▪ If you're interested

1. Call 415-502-3500 or email star@ucsf.edu
 - intake with clinic coordinator, will check insurance
2. If appropriate, assessment or intake appointment will be scheduled
3. Will be sent/given questionnaires to complete
4. Meet with group leaders

What to expect if you enroll in a group

- Will be asked to participate in research
 - Decision does not affect eligibility or service
- Commitment to attend regularly is essential!!!
- Limits of confidentiality in a group setting
 - Includes expectation that you will maintain others' confidentiality!

Coming soon...

- **Mental Health groups**

- Cognitive Behavior Therapy
- Behavioral activation for adults w/ intellectual disability

- **Enhancing independence/adaptive behaviors**

- **Training for Paraprofessionals working w/ adults**

Discussion

- Program specific questions?
- Questions about program considerations?
- Suggestions for programs we should develop?

How to Contact Us:

Website: www.star.ucsf.edu

Clinical Coordinator: Elise Evangelista at 415-502-3500 or star@ucsf.edu

Address: UCSF Parnassus Campus
401 Parnassus Avenue
San Francisco, CA 94143

