

JULY 2026

BUFFALO, NEW YORK

**A qualitative study on the transition to
adulthood for youth with Williams syndrome:
Family insights and practice implications**

PRESENTED BY

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Presented by

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WSA 2026 
CONVENTION

Breakout Session

OVERVIEW

- We know little about the experience of adolescents and young adults with Williams syndrome and their families navigating the transition into adulthood.
- We interviewed 15 people with WS and their loved ones together about their priorities and goals as they transition to adulthood; we generated six critical themes from their experiences.
- We provide practical suggestions for clinicians and families about navigating the start of adulthood based on our clinical experience.

Learning objectives

BY THE END OF THE SESSION ATTENDEES WILL BE ABLE TO:

- Name five domains of adulthood to consider for a youth with WS leaving high school
- Identify an area of strength that promotes better mental health and quality of life
- Name at least two needs for the young adult with WS during the transition to adulthood

Acknowledgements

FUNDING SOURCES:

- Armellino Center of Excellence for Williams Syndrome
- The Kim Family Fellowship in Williams Syndrome
- National Institute of Child and Human Development

Dr. Ben Yerys



Associate Professor

Director, Advancing Transition and Learning for Adult Success (ATLAS)

Research Team Member in the ACE-WS

Children's Hospital of Philadelphia/University of Pennsylvania

BIOGRAPHY

Dr. Benjamin E. Yerys, PhD, is a licensed psychologist with more than 20 years of research and clinical experience. Dr. Yerys has long supported youth with neurodevelopmental conditions. Dr. Yerys' research focuses on how the development of attention, executive function, and reward-based learning impact people's ability to complete daily living skills, their mental health, and their overall quality of life. Dr. Yerys aims to take insights gained from research and immediately translate them into clinically actionable steps – new treatments, assessment tools, and recommendations for families.

FLIGHT-WS TEAM



Ariana Garagozzo
PsyD*



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PsyD*



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MPH



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BA

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Talk Outline

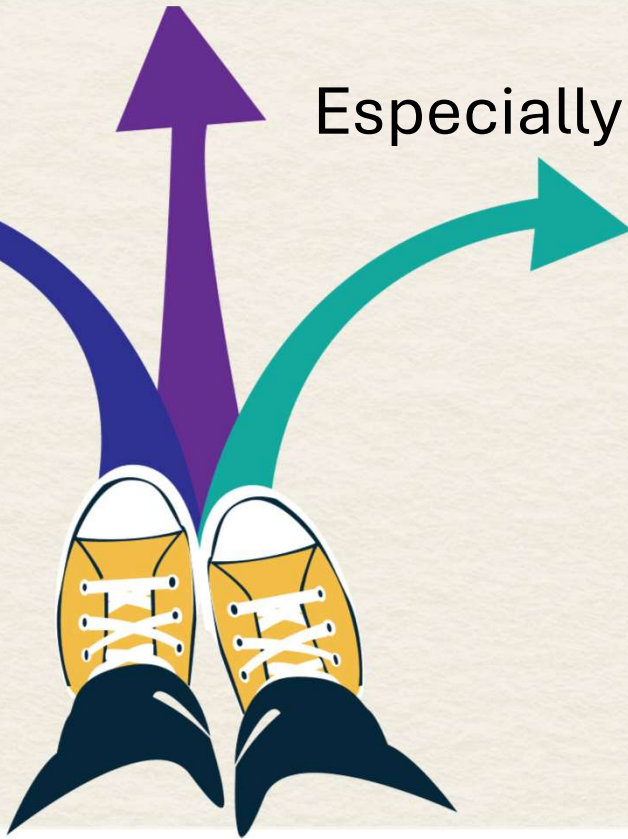
WE WILL ADDRESS THE FOLLOWING QUESTIONS:

- ☐ What do we mean by the transition to adulthood?
- ☐ What did we learn from teens and young adults with WS and their families?
- ☐ How do you translate these findings into actionable steps?

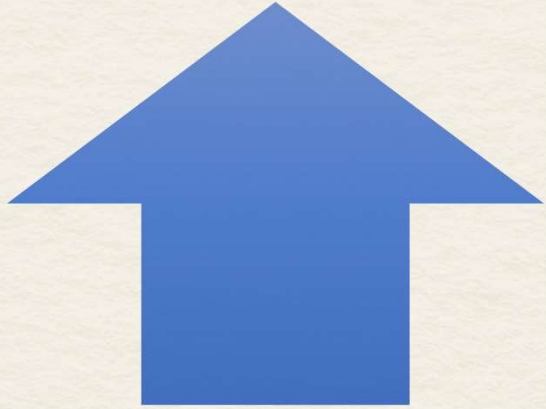
Transitions are Stressful

Especially the transition to adulthood!

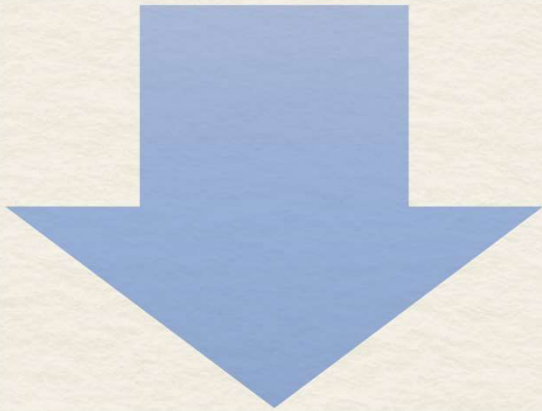
- Changes in environments
- Changes in social demands
- Physical changes
- Changes in care providers
- Changes in expectations



Transition to Adulthood



Increasing normative expectations for independence



Decreasing access to services and supports

Service Cliff

- Shortage of adult providers specializing in WS
- Fewer supports available after high school because there are no federal mandates for accommodations



Changes to Service Provision

- Service provision for **children in schools** is based on an entitlement system
 - Students with disabilities are entitled to services through their districts
 - Law requires schools to provide free and appropriate public education, as defined by student's IEP
 - Services are provided regardless of family income
- Service provision for **adults** is based on eligibility system
 - Individual must meet eligibility requirements AND meet financial guidelines
 - Person may qualify for services, but not receive them due to funding/staffing/etc.

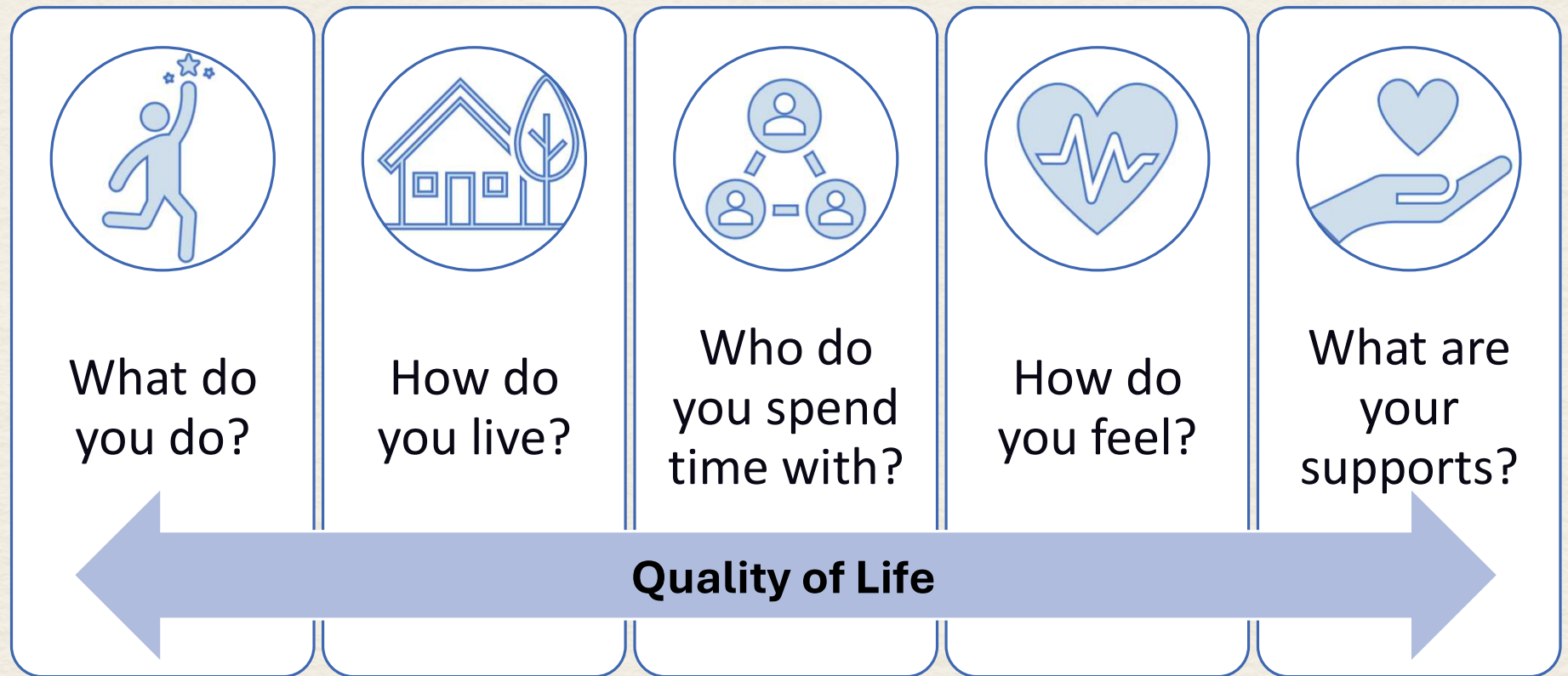
What is our mission for serving transition-aged youth in the WS community?

- Support teens and young adults with WS and their families to gain access to federal funds and needed services
- Decrease (some) family stress about the ‘unknown unknowns’ about adulthood

Fostering Life, Independence, Growth and Healthy Transitions (FLIGHT)

- A first-of-its-kind study focused on 14- to 25-year-olds with WS who are navigating adulthood
 - What are your priorities, goals, and needs?
 - What skills drive the development of daily living skills?
 - What factors are most important for experiencing a higher quality of life?

Guiding Model for ATLAS



Guiding Model for ATLAS



What do
you do?



How do
you live?



Who do
you spend
time with?



How do
you feel?



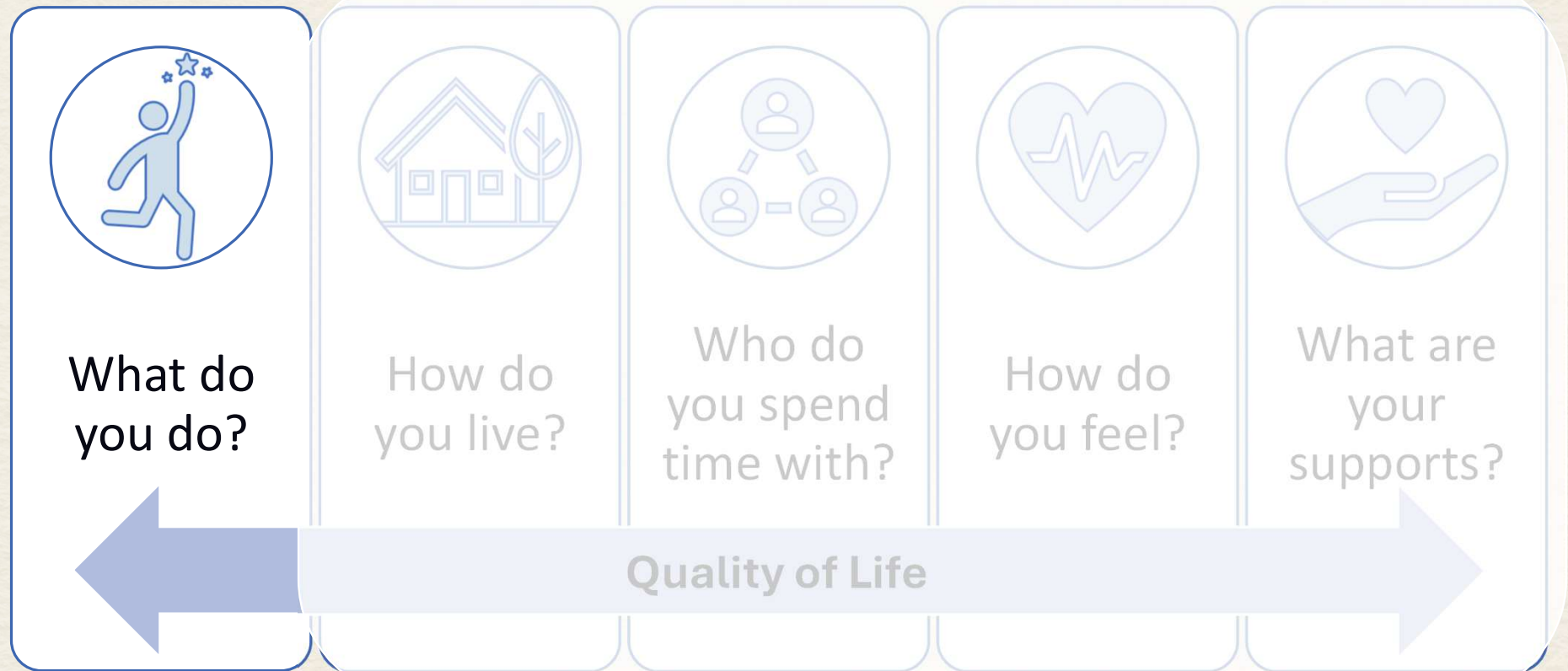
What are
your
supports?



ELIGIBILITY FOR SUPPORTS

- Medicaid (Health Insurance)
- Medicaid Waivers
- Supplemental Security Income (SSI)
- Supplemental Nutrition Assistance Program (SNAP)
- ABLE Accounts/Special Needs Trusts
- Power of Attorney/Guardianship (Limited and Full)
- Office of Vocational Rehabilitation

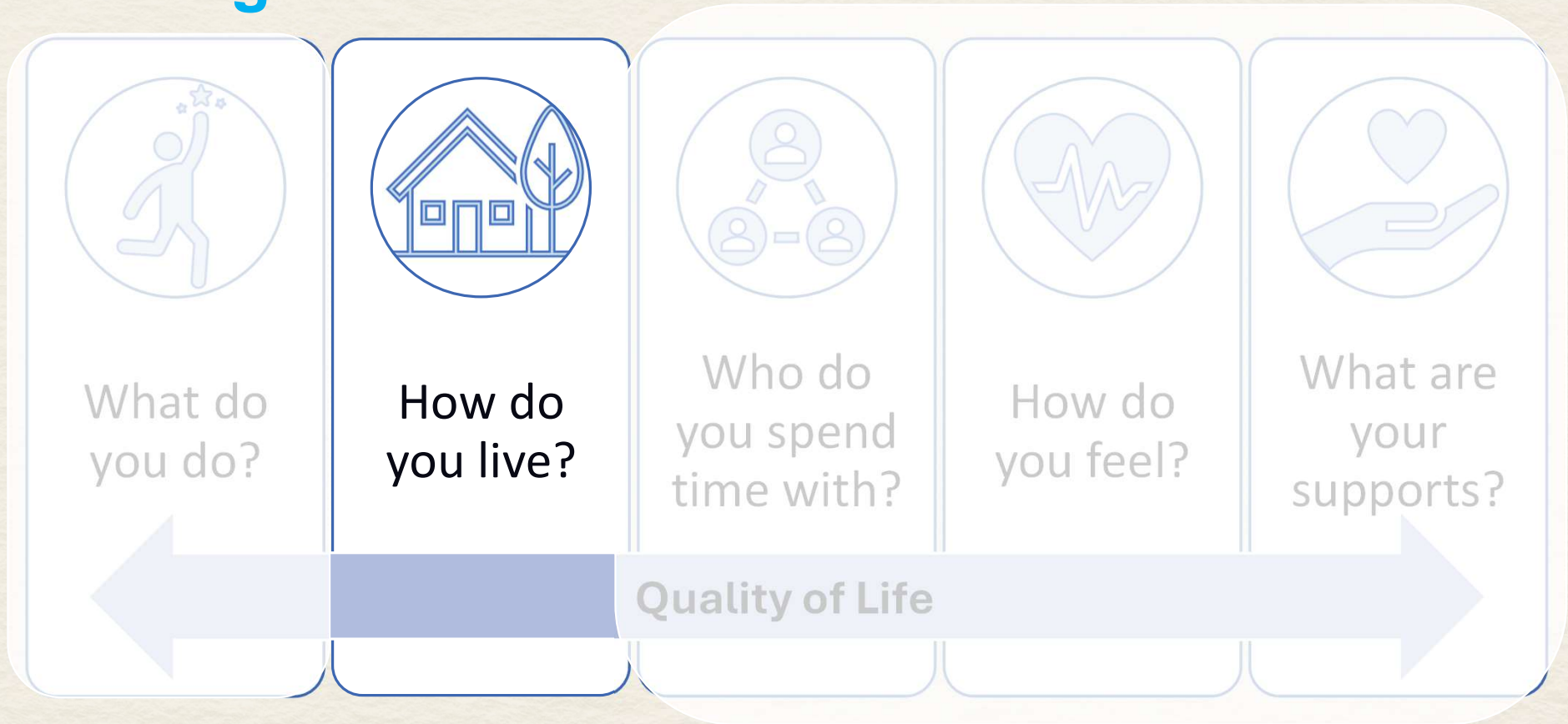
Guiding Model for ATLAS



Education and Employment

- College Support Programs
- Academic Accommodation Requests
- Employment Accommodation Requests
- Employment Resources and Networks

Guiding Model for ATLAS

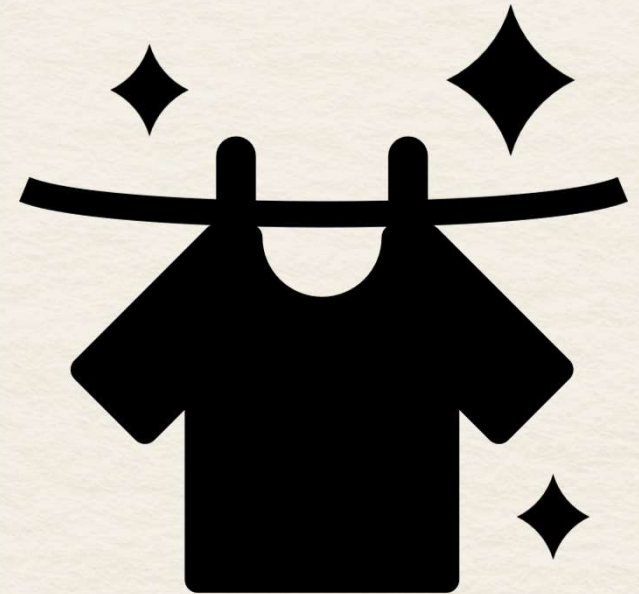


Daily Living Skills

SKILLS FOR INDEPENDENCE

- Hygiene
- Cleaning
- Cooking
- Laundry
- Financial Literacy

Occupational Therapy to Build Daily Living Skills



Housing

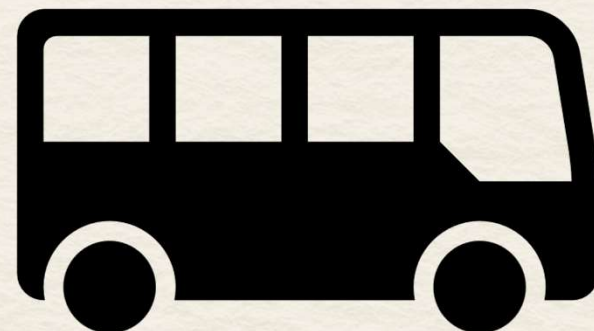
LIVING OPTIONS

- Independent Living
- Supervised Living
- Supportive Living

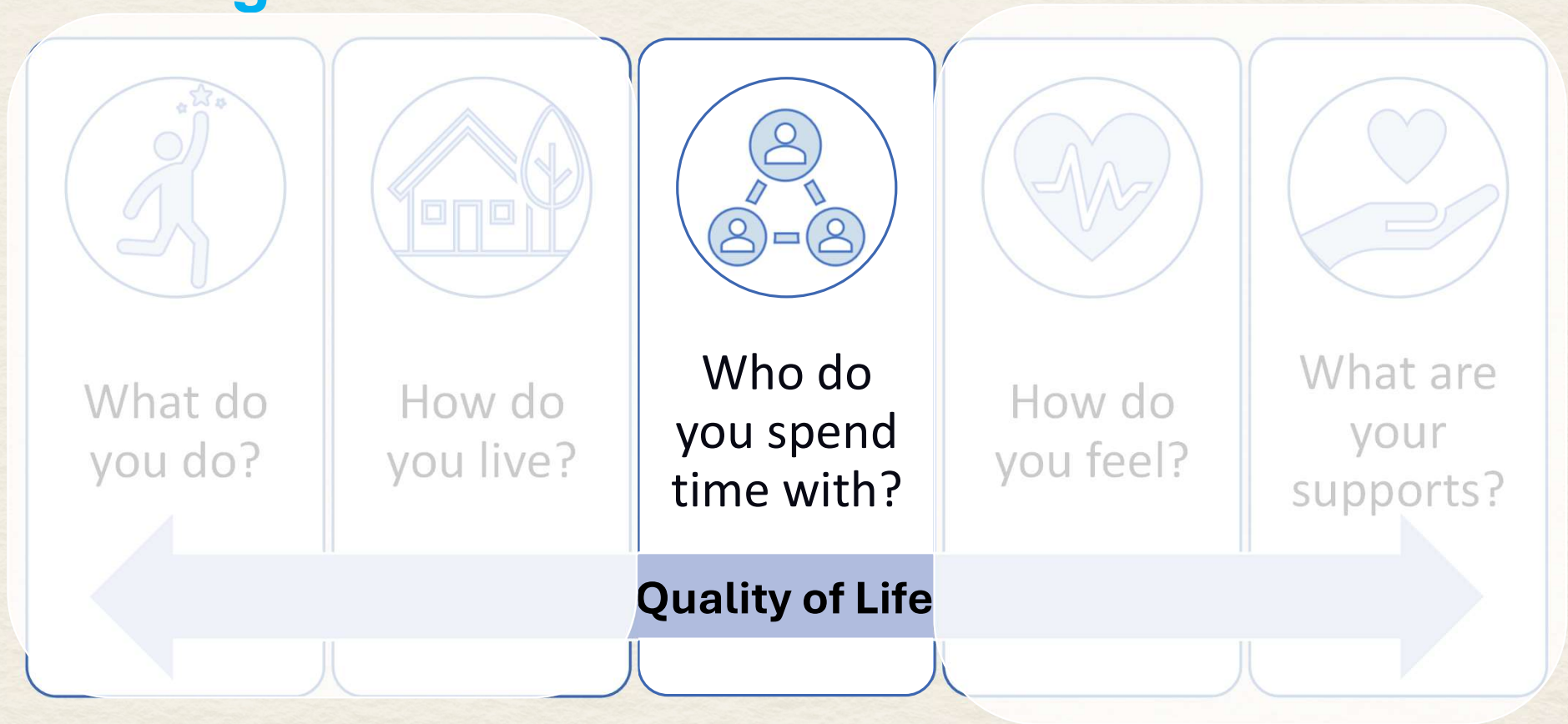


Transportation

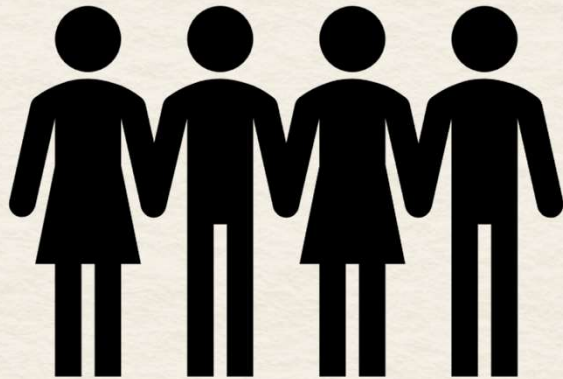
- General Transportation Toolkits (Beth Pfeiffer, Temple U.)
- Ridesharing Resources (Uber's Simple Mode)
- Local Public Transit May Provide Training Programs
- Medicaid Waiver can cover transportation
- Driving Evaluations and Specialized Instructors



Guiding Model for ATLAS

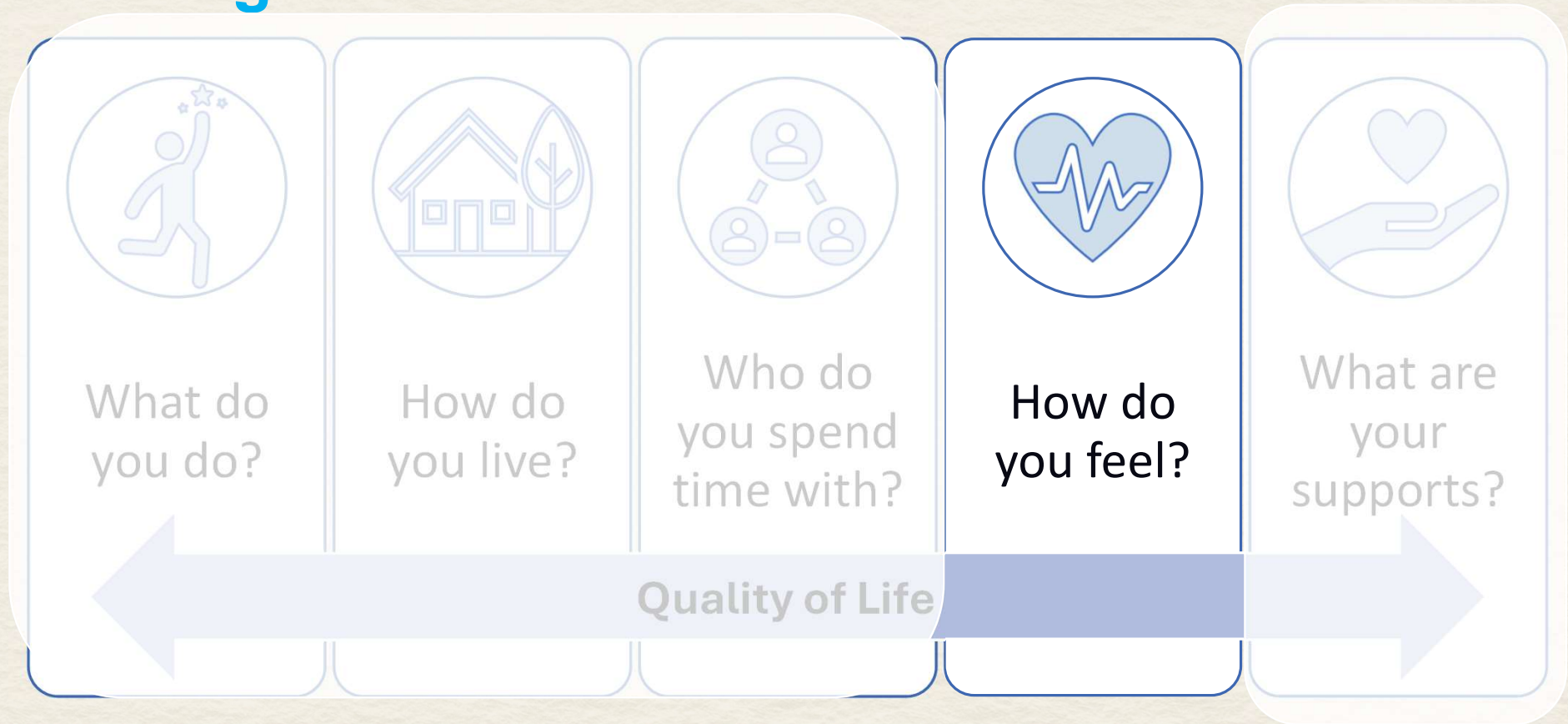


Community



- Connecting with IDD and Neurodivergent Communities
- Connecting to Communities Around Interests
- Virtual + In-Person Opportunities
- Platonic and Romantic Relationships

Guiding Model for ATLAS

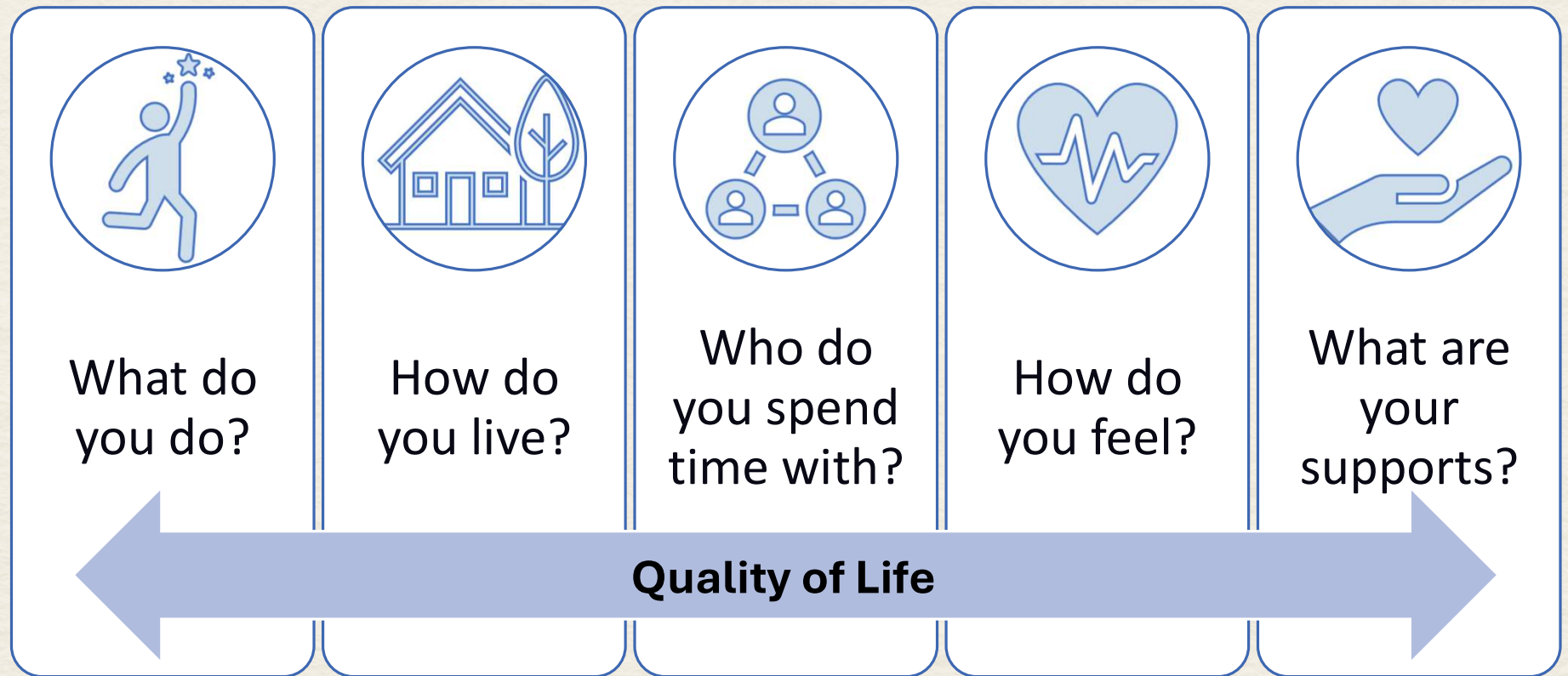


Medical + Mental Health Care

- Recommendations for Adult Primary Care
- Recommendations for Adult Therapists

Armellino Center of Excellence for Williams Syndrome is aiming to fill this important healthcare gap

Guiding Model for ATLAS



Talk Outline

WE WILL ADDRESS THE FOLLOWING QUESTIONS:

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- ☐ How do you translate these findings into actionable steps?

Amplifying the Voices of the WS Community

THE BENEFITS OF A QUALITATIVE STUDY

- Provide an opportunity for families to answer open-ended questions about the transition to adulthood
- We report the themes that emerge from the interviews so the voices of the WS community are emphasized over scientific hypotheses
 - “Hypothesis generating NOT hypothesis testing”

Participant Characteristics	Total Sample (N=16)
Age Mean (SD)	19 years, 8 mos. (3 years, 3 mos.) Range = 15 – 25 years
Full-Scale IQ Standard Score Mean (SD)	51 (6) Range = 44 - 70
Sex	Female 50% Male 50%
Race	Asian 6% Black 6% More than One Race 6% White 81%
Ethnicity	Hispanic 6% Non-Hispanic 94%
Co-Occurring Mental Health and Neurodevelopmental Diagnoses	Autism 50% ID 50% Anxiety 50% ADHD 44%

Method: Interview

Transition to Adulthood Clinical Interview Domains and Questions

Academics

Are you in high school? ☐ Yes
☐ No

What year of high school are you in? _____

What year are you? ☐ Freshman
☐ Sophomore
☐ Junior
☐ Senior
☐ Transition Program

Do you have an IEP? ☐ Yes
☐ No

What accommodations do you receive? _____

Do you plan to attend a transition program? ☐ No
☐ Yes
☐ Unsure

What is your anticipated year of graduation? _____

What year did you graduate? _____

Are you interested in going to college? ☐ No
☐ Yes
☐ Not asked (not clinically indicated)

Academics Notes: _____

Employment

Do you have a job? ☐ Yes
☐ No

What do you do? _____

Method: Interview

Confidential

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Financial Considerations

Have you made your own purchase? (ex. buying chips at a store) ☐ Yes ☐ No

Have you saved money? ☐ Yes ☐ No

Have you paid a bill? ☐ Yes ☐ No

How do you feel about managing money?

Financial Considerations Notes:

Housing Plans

Where do you want to live? ☐ House ☐ Apartment ☐ Other (open field)

Other

Who do you want to live with? ☐ Parents ☐ Siblings ☐ Friends ☐ Roommates ☐ Romantic partner ☐ Self ☐ Other

Other:

What kind of housing supports do you think would be helpful for you? (ex. Someone to help with laundry, cooking)

Housing Plans Notes:

Method: Positionality and Theme Generation

POSITIONALITY

- Authors analyzing data identify as neurotypical
- Dr. Garagozzo identifies as the sibling of an adult with a rare genetic syndrome which may influence her attunement to the family experience

Theme Generation

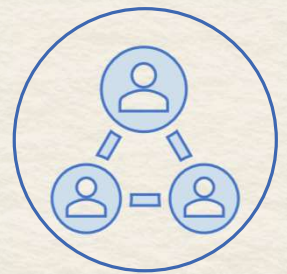
- Reflexive thematic analysis
 - Review interviews, generate codes and themes, review themes, define and name themes,

Interview Themes

Themes	Definition
Community Engagement	Engaging in organized activities and hobbies, volunteering, religious participation, WSA activities, platonic and romantic relationships
Social Vulnerability	Potential for exploitation by others
Service Access	Government Services
Daily Living Skills	Self-Care (hygiene, taking medications), Home Care (laundry, cleaning), Community Care (grocery shopping)
Financial Literacy	Store purchases, budgeting weekly and monthly expenses, monitoring spending/bank account, paying taxes, long-term financial planning
Housing & Future Planning	Living independently or with support in the short- and long-term

Community Engagement

- Community engagement is a strength!
- Almost every young adult was involved in some type of structured and supervised community activity
- Families described these activities as important opportunities for:
 - social connection
 - building confidence
 - taking on more adult responsibility
 - practicing daily living skills in the community



Social Vulnerability

- Caregivers reported that young adults' hyper-sociability left them vulnerable to exploitation when in unsupervised settings:
 - Work
 - Using Rideshare services
- These concerns affected families comfort with encouraging their young adults to have more independence

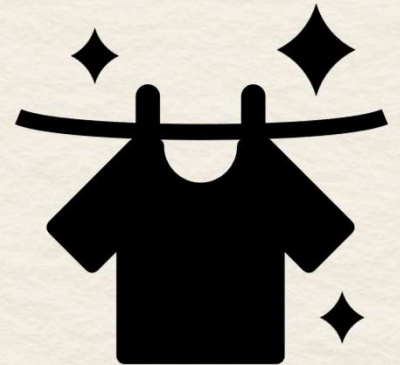
Service Access

- Navigating adult services is one of the most difficult parts of the transition to adulthood
 - Taxing to navigate multiple systems simultaneously
 - Application processes are long
 - Eligibility requirements are confusing
 - Difficulty knowing where to start
 - Fear of 'unknown unknowns'
 - Frustration when the young adult does not qualify for services they expected to receive



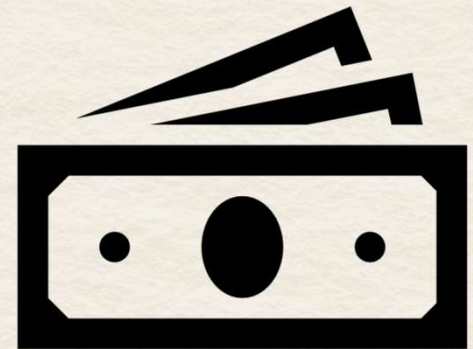
Daily Living Skills

- Most young adults were independent with basic self-care daily living skills
- Most young adults needed support with more complex self-care (shaving, medication management), home-care (cooking, laundry), and community care tasks (grocery shopping)
- Caregivers feel young adults have difficulty remembering, getting started, and finishing daily living skills without prompts and reminders



Financial Literacy

- Young adults and families agree that young adults need and want support managing money
- Many young adults make basic purchases
- Caregivers are responsible for all other money management
- Caregivers anticipated their young adults needing lifelong support for money management



Housing & Future Planning

- Young adults want to live independently or with some level of support
- Caregivers want appropriate housing options and planning for a time when they would no longer be able to provide support
- Families want more guidance from providers about long-term planning for housing and supported living options



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Clinical Implications: Providers

- Teach families about accessing government services that provide financial resources and vocation or education support
- Embed Occupational Therapy targeting daily living skills into transition to adulthood programs for adolescents and young adults
- Explore the extent to social vulnerability is amenable to change (SSTP-WS)
- Develop evidence-based **Community Safety** programs for adulthood

Clinical Implications: Families

FAMILIES

- Community Engagement provides multiple benefits beyond social connection
 - Practice daily living skills
 - Gain employment skills
 - Practice self-determination
 - Build confidence and independence
- If you are confused about services or unsure of long-term planning, then ask questions of providers or AI (it's not bad at simplifying application instructions!)

Conclusion and Future Directions

- Our study identified **strengths and needs** in the transition to adulthood for youth with WS
- Community engagement may be a resilience factor as our broader study shows very low rates of depression
- Barriers to accessing services, social vulnerability, and challenges in daily living skills/financial literacy **are urgent areas for intervention**

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Thank You!

Thank you to our presenting sponsor for
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