

# Building a Career: Emerging Considerations for a Nurturing 'Ecosystem' in Employment and Autism

Fifth Annual Autism  
Public Health Lecture:  
A.J. Drexel Autism Institute

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# Objectives

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1. To explore experiences of employment and employment support: self advocates, parents/caregivers, service providers, employers



2. To examine an emerging ecosystem perspective

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# Examining Employment Support for Adults with Autism Spectrum Disorder

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AIM: To examine employment support experiences

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# 1. Survey of Employment Support Resources: n=137

## 2. Key Informant Interviews

- Self advocates: n=51
- Parents/Caregivers: n=71
- Service Providers: n=42
  - Employers: n=22

## 3. Modified Delphi Consultation

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# Delphi Consultation

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- ▶ **Review of findings across jurisdictions**
  - ▶ Diverse stakeholders in small groups
  - ▶ Convenience sample
  - ▶ Self advocates, parents/caregivers, service providers, employers, program & policy planners
- ▶ **Advancement of findings to inform practice, theory and policy**





**Ecosystem:** A community of interacting organisms in the context of their environment

# Employment and ASD

*Shattuck, Narendorf, Cooper, Sterzing, Wagner & Taylor, 2012:*

## 1. **No participation in post-secondary education or employment**

(by years since high school exit) (National Longitudinal Transition Survey 2):

**<1: 58.5%**

**1-2: 51.9%**

**2-3: 28.9%**

**3-4: 14.3%**

**4-7: 11.1%**



2. Compared to those with learning disabilities, mental retardation and speech/language impairment, **individuals with ASD demonstrate significantly lower rates of employment**

*Bizier, Fawcett, Gilbert, & Marshall, 2015:*

Only **22%** of working age adults with ASD are employed





# TRANSITION: From adolescence to where?

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“It went from, like support in high school and then, it’s not as much support... Once they go into their later years, there isn’t really any support... for adults. And no one ever really knew what would happen with adults with autism.”

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# Mother of an adult with ASD

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“What my son needs now is job skills... He needs to survive in this world as a young adult, with or without his parents. Help! Because not every young adult with autism has parents or has the supports, right? Whether it be parents or other family members, not everyone has that. So he needs job skills; he needs life skills & life training.”

# Employment Programming with Favorable Outcomes

(Hedley, Uljarevic, Cameron, Halder, Richdale & Dissanayake, 2016)

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- ▶ **TEACCH Program:** Training and job coaching in situ
  - ▶ over ~10 years, 96% placement in jobs (job retention rate of 89%) (Hinton Keel, Mesibov & Woods, 1997)
- ▶ **Project SEARCH:** Internship program for youth in final year of high school, with environmental support
  - ▶ 88% in competitive employment vs. 6% of youth who received services based on an Individual Education Plan (Schall et al, 2015; Wehman et al, 2012a, 2012b, 2014)
- ▶ **National Autistic Society (NAS) Prospects Program:** Supported employment service model
  - ▶ 68% in 192 jobs over an 8-year period, with employer capacity building (Howlin, Alcock, & Burkin, 2005)



## Vocational Skills Interventions: 21 (Seaman, Canella-Malone, 2016)

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- ▶ **Pre-employment: 3** (all evaluated, using group designs)
  - ▶ 3 at universities, 0 at worksites
- ▶ **Job tasks: 14** (all evaluated, using single case designs)
  - ▶ 13 using technology; 7 at worksites, 7 at schools/universities
  - ▶ Restaurant (2), Retail (7), Clerical (5)
  - ▶ 9 (62%) used video modelling or prompting
  - ▶ 3 (21%) used audio coaching
  - ▶ 2 (14%) used behavioral skills development/training
- ▶ **Job retention: 4**
  - ▶ 3 (75%) using technology; 3 in workplace, 1 at a university



## Evaluation (Seaman, Canella-Malone, 2016)

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- ▶ **Group design: 6 (29%)**
- ▶ **Single case design: 15 (71%)**
  - ▶ 9 studies met evidence standards without (6) or with (3) reservations  
(What Works Clearinghouse Single Case Design Standards)
- ▶ **7 (33%) assessed generalization**
- ▶ **12 (57%) assessed maintenance**



# Emerging Considerations

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- ▶ Limited studies (generally poor to moderate quality)
- ▶ **Gaps** (Seaman et al, 2016)
  - ▶ Pre-employment (e.g., core skills, resume writing, interviewing, occupational focus, motivation)
  - ▶ Job retention (e.g., social reciprocity, navigation of the work environment, demands and relationships)
- ▶ **Require time and breadth of experience - to acquire skills and practice**
  - ▶ Invite early engagement
  - ▶ Invite wider employment sampling
- ▶ **Promising elements**
  - ▶ Technology (audio/video modelling/prompting)
  - ▶ Behavioral approaches

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▶ (Hedley et al, 2016 Seaman et al, 2016)

# Summary

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- ▶ Emerging evidence of benefit from employment support
- ▶ Insufficient granular understanding about mechanisms toward change (and for whom)
- ▶ “Meaning” and “context” of employment unclear: identity formation, self esteem, independence, relational expansion, income generation, community integration, quality of life, GDP (decreased caregiver and public cost, increased productivity), contribution





“...(A) life course public health lens... demands investigation of the social-ecological context of employment. Our developmental theories generally support a

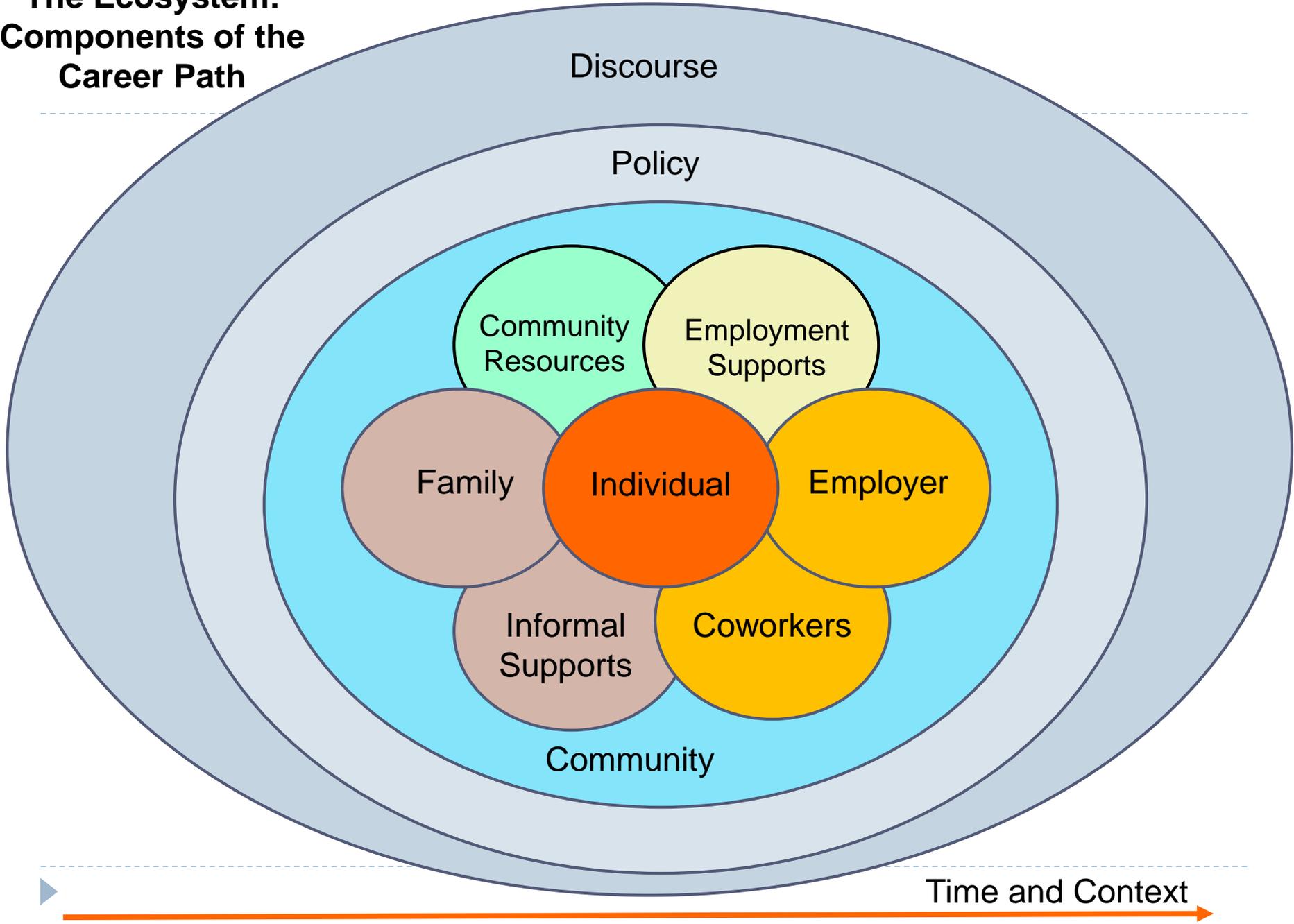
bio-psychosocial framework for understanding disability (WHO, 2001). However, the vast majority of scientific thinking and inquiry in the field of autism hovers at the biological and psychological levels.

Unemployment is not just an individual predicament, it is a social problem. Social problems cannot be solved entirely through a focus on modifying individual behaviors and abilities, although this is certainly an important pursuit. We also need to examine the social environment and the impact of interventions targeting a community or policy level.

(Shattuck, PT & Roux, AM [2015], Commentary on employment support research. *Autism*, 19[2], p. 246)



# The Ecosystem: Components of the Career Path



# Getting a job isn't just getting a job...

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- ▶ 'Complex' multi-factorial issue
- ▶ Single response or approach may minimize relevant elements (Thompson et al., 2009)
  - ▶ Disability + poverty + lack of employment/income + health/mental health issues + transportation challenges + education issues
- ▶ Larger linked network of intersecting components and systems (Buntinx & Schalock, 2010)



# Ecosystem Components: Employment

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## Community Resources

- Service availability and access
- Information navigation
- Policy framework

## Individual Support

- Job preparation: job skills, life skills
- Job access: fit
- Job retention & advancement support



## Family Navigation and Support

- Honoring family role
- Augmenting/easing family role

## Community/Workplace Capacity

- Organization/employer capacity enhancement
  - Workplace adjustments (e.g., sensory, environmental, challenge management)

# 1. The Individual

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- ▶ **Job readiness**
  - ▶ Vocationally-relevant aptitudes
  - ▶ Job-specific skills
  - ▶ Work experience
- ▶ **Foundational considerations**
  - ▶ Personality, interests, motivation, cognition, communication methods, behaviors, sensory sensitivities and well-being
- ▶ **Sectoral traits and skills (e.g., team work)**
  - ▶ Confidence
  - ▶ Communication proficiency

(The Panel on Fair Access to the Professions, 2009)

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# Higher Odds of Participation in Employment/PSE

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- ▶ Absence of intellectual disability
- ▶ More subtle ASD expression
- ▶ Functional ability
- ▶ Increased time out of high school
- ▶ Paid work experience in high school
- ▶ Higher family income
- ▶ Ethno-cultural background

(Hedley et al, 2016; Roux, Shattuck, Rast, Rava, & Anderson, 2015; Shattuck et al, 2012; Taylor & Seltzer, 2011; Wei et al, 2015)

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# Challenges

## EMOTIONAL/PSYCHOLOGICAL CHALLENGES

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- anxiety, strain
- lack of confidence
- self-esteem

## FOCUS/CONCENTRATION

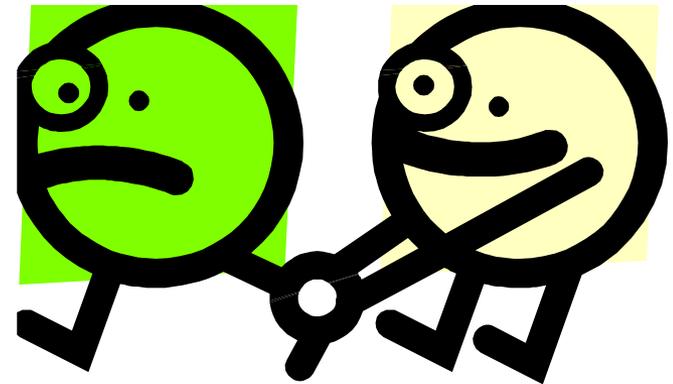
- “can’t think about doing four things at once... can focus on one”
- Varying challenges: study for hours & see patterns, but can't remember

## ENVIRONMENTAL/PROCESSING

- sensory issues
- verbal details
- time insufficient to process tasks or emotions/situations

## SOCIAL/RELATIONAL

- colleagues/supervisors
  - others not direct
  - “too honest”
  - direct communication viewed as blunt
  - difficulty with strangers
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# Work-related Anxiety

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The problem is I can do the job well, but I get anxious on the job because I'm comparing myself to other people and I'm analyzing. I don't... do the job like other people. I see the power dynamics and the way it treats people and it gets to me you know. Because I'm passionate about the job and I don't like it when other people are not passionate about their jobs. It's horrible, I hate it.

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- ▶ Physical/Biological Issues (e.g., sleep, attention)
  - ▶ Job Structures/Demands (e.g., tasks too great, “not enough time to recuperate”, “You can’t have meaningless rules that muddle up my mind.”)
  - ▶ Disclosure of ASD
  - ▶ Logistical Issues (e.g., travel/transportation)
  - ▶ Market Issues (e.g., few jobs, difficulty competing)



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## 2. Employment Services

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# Elements of Employment Support...

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## Skills Development & Strategies

- ▶ Help with job skills and social skills
- ▶ Strategies for timely task accomplishment
- ▶ Time to process emotions
- ▶ Visual triggers to facilitate memory retrieval
- ▶ Scripted role play/use of technology
- ▶ Clarity of tasks and processes (tasks broken down)

## Navigator/Advocate

- ▶ Employer open to support person during orientation
- ▶ Follow up with employer
- ▶ Individualized support
- ▶ Support in crisis



### 3. Employer, Co-workers, Workplace



# Employer Capacity

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- ▶ Supportive involvement of HR or management
- ▶ Some knowledge about autism *and* autism in the workplace
- ▶ Open communication between HR/employer and employee
- ▶ Amenability to employment support
- ▶ Feedback mechanisms



# Job Fit

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- ▶ **Position offers good fit with the skills/aptitudes of the individual**
  - ▶ Consistent with interest
  - ▶ Commensurate with skills and strengths
  - ▶ Individuals are permitted to work from their skills and strengths, rather than from limitations or avoiding weaknesses
  - ▶ Balance in reaching to skills while generally avoiding areas of challenge



# Workplace Environment

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- ▶ Clear, achievable job expectations
- ▶ Attention to detail
- ▶ Active communication including “checking in”
- ▶ Opportunity for skill development
- ▶ Sensory accommodation
- ▶ Calm atmosphere
- ▶ Person-centeredness – oriented for success
- ▶ Mutual understanding and respect for involvement and support (balanced support/two-way support)



## 4. Broader Community Resources and Supportive Public Policy

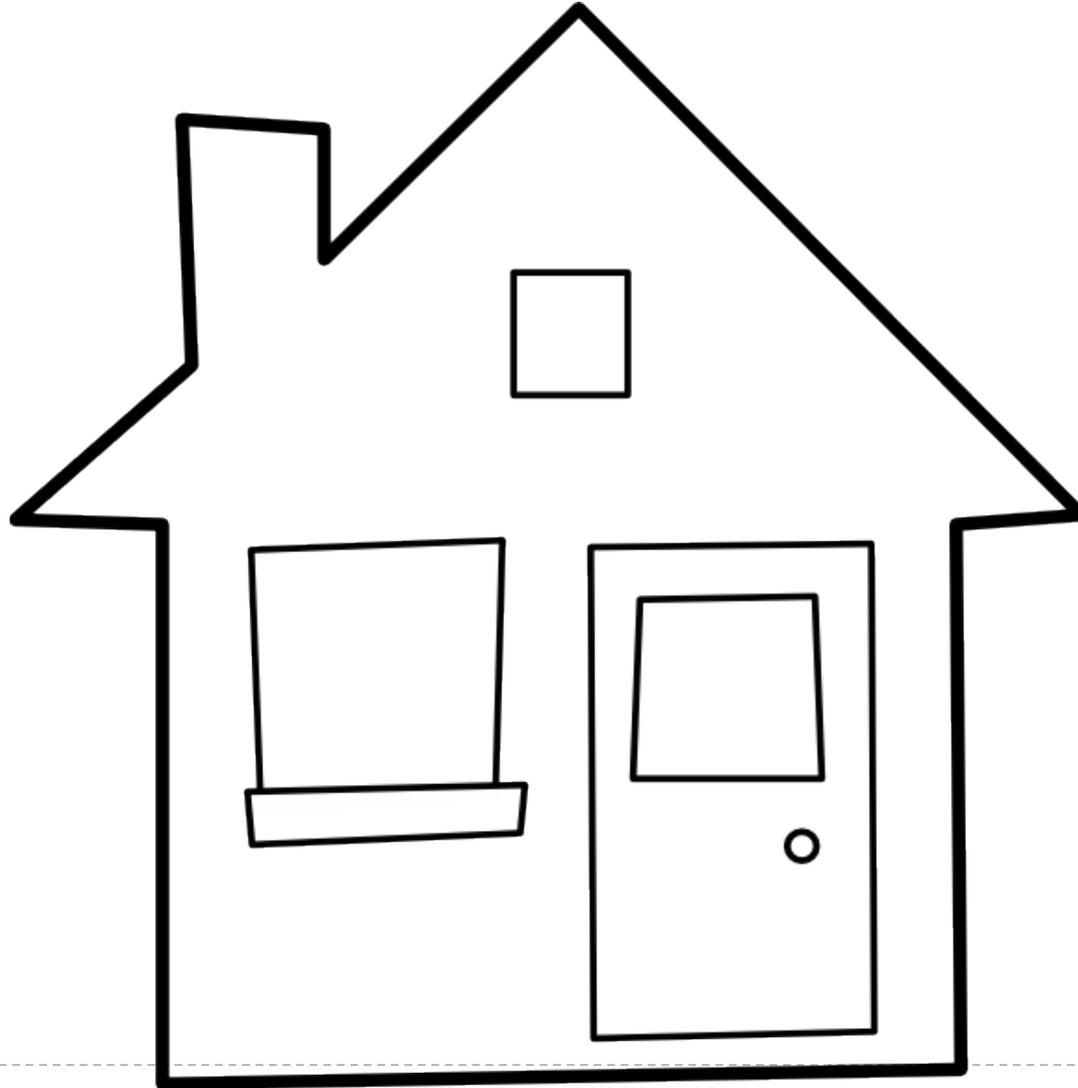
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- ▶ Quality housing, transportation, health and mental health services, income sufficiency, food security, and leisure opportunities
- ▶ Social, labour, economic and health policy
- ▶ Social determinants of health



# 5. The Family

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# Family Roles

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- ▶ Engage, navigate and buffer
- ▶ Fund services & other opportunities
- ▶ Nurture generalization of learning
- ▶ Offer ‘decompressional’ support related to job and life challenges



# **System Collusion or Collision?**

Family System

Employment System

Broader Discourse

- ▶ Role of the family relative to employment?
- ▶ Sociocultural discourse:

Adulthood = Independence

Independence = Employment

Employment  $\neq$  Family engagement



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# Discursive Context

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# Quality of Life

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- ▶ **“Being, Belonging, Becoming”**

(Raphael, Brown, Renwick, & Rootman, 1996)

- ▶ Being who you want to be
- ▶ Welcoming environment, citizenship
- ▶ Pursuit of aims

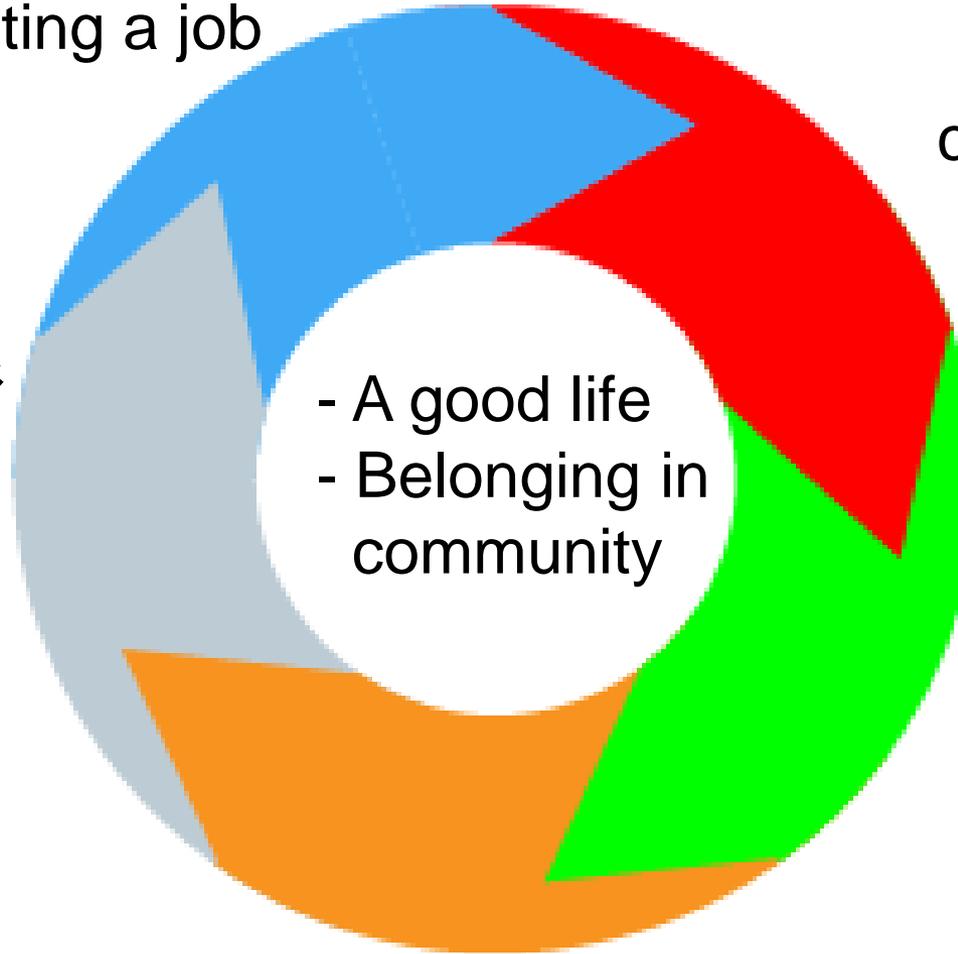
“the degree to which a person enjoys the possibilities of her/his life” (Raphael et al, 1996, p. 28)



Getting a job isn't just getting a job

Getting a job isn't creating a meaningful career (although a job is an important part)

Meaningful & sustained employment reflects a supportive ecosystem



Getting a job or creating a career may not be the pinnacle

Quality of life can be enriched by meaningful employment

# Limitations

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- Retrospective data
  - Lack of integration of findings with employment outcomes (exploratory)
  - Convenience sample in specific regions
  - Potential under-representation (e.g., females with ASD, range of ASD expression, SES, ethno-cultural diversity, rurality)
  - Lack of granular analysis of sample distinctions or interventional approaches
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# Research Recommendations

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- Research partnerships in community
    - Participatory/community models
    - Data sharing for program utilization/quality improvement
    - Intervention/model-based research
    - Longitudinal and life course designs
  - Broad inclusion in samples: age, ASD expression, ecosystem, other issues (e.g., mental health), social determinants, etc.
  - Engagement of self advocates
  - Examine family experience and outcomes
  - Development of metrics and methods of assessment at individual, program and community levels
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# Implications

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- Early exposure and prolonged support
- Broaden work sampling
  - Varied sectors/employment settings
- Use of technology (e.g., audio/video prompting)
- Learning in environment
  - Focus on generalization
  - Real-world application



# Implications and Conclusion

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- Increased resources to support ‘paths’ to career
  - Transition planning, vocational fit, support, employer capacity building, broader service access and navigation, family support
- Heightened consideration of the ecosystem
- Collective action
  - Timely mobilization of evidence to integrative action
  - Engagement of relevant systems/stakeholders
- Proactively address the social determinants of health
- Greater focus on quality of life over the life course



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