

## Examining the Transition to Adulthood in Autism: Challenges & Opportunities in the Aim of Thriving

Autism Research Institute &  
World Autism Organization

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## Objectives

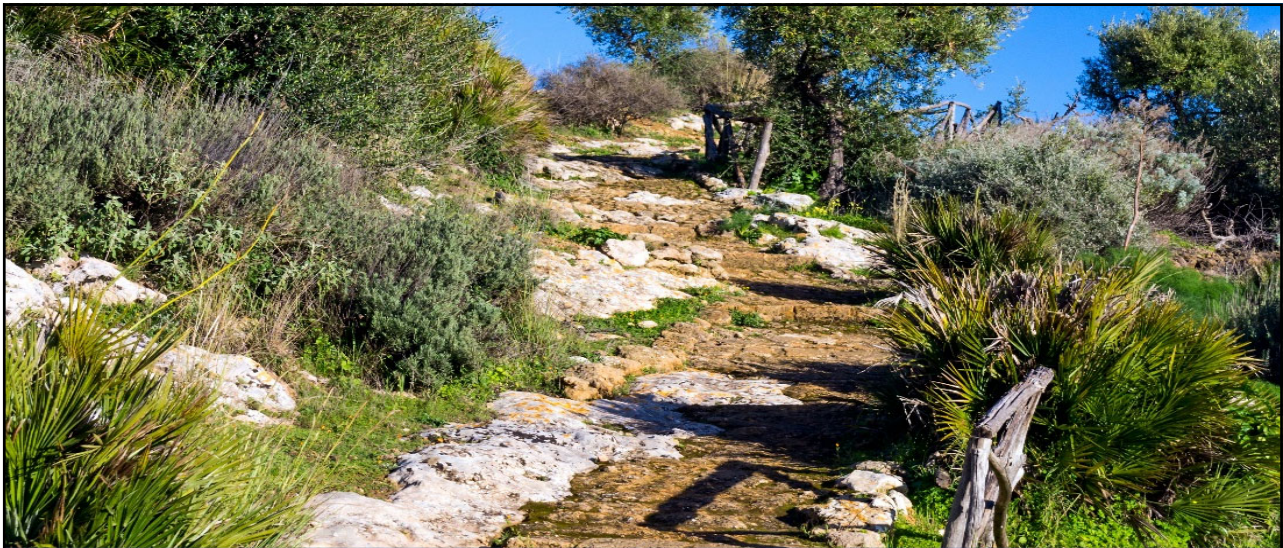
1. To explore experiences of transition: autistic youth and adults, parents/supporters, service providers



2. To examine an emerging ecosystem perspective: employment, post-secondary education, service navigation

## Perspectives of the Transition Literature

- Support needs not well-understood (Shattuck et al, 2018)
- Interventional literature largely focused on behavioral outcomes (Bottema-Beutel et al, 2023)
- Research gaps
  - Limited # of evaluation studies (Bottema-Beutel et al, 2023)
  - Quality/design issues (Bottema-Beutel et al, 2023)
  - Lack of longitudinal research (Shattuck et al, 2018)
  - Lack of first person involvement (Shattuck et al, 2018)
- Little accounting for pandemic impacts/implications
- Priorities: ↑ QoL orientation, and  
↑ community/system level factors (Shattuck et al, 2018)



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





## **Methods** (Nicholas, Jubenville-Wood, Zulla, Lowe & Zwaigenbaum, 2023)

- Semi-structured interviews:
  - Autistic youth/young adults (13-15-years, 16-17 years, 18-19 years, 20-21 years, 22 years and older)
  - Parents
  - Service providers
- Grounded Theory approach: open, axial and selective coding (Corbin & Strauss, 2014)
  - Data broken down into discrete units of meaning
  - Identified meaning units coded and assembled through constant comparison to form categories
  - Categories examined for their relationships and conceptual context

Participants	Age (in years)	Total males	Total females
Autistic Youth	13-15	7	0
	16-17	3	1
Autistic Adults	18-19	3	1
	20-21	5	1
	22-42	9	1
Parents	35-61	3	20
Service Providers		3	7
<b>TOTAL</b>	<b>N=64</b>		

## Results: Transition can be frustrating and arduous, with a lack of navigational guidance

- “Fighting” for services while often being unsure about how to proceed or what to seek
- Needing to research, find and wait for services
- Multiple forms and laborious application processes
- Adult system notably distinct from child/youth services
- Multiple and convoluted routes to services
- Lack of assistance with the transition process

“It’s all mountains of paperwork and if you don’t have a person in your life who’s willing to take the time to fill out [forms], research, and do it, nobody would do it for [the autistic individual].”



### **Inhibiting or Unhelpful Processes and Attitudes**

- Services frequently insufficient relative to need (e.g., skill development, health/mental health care, post-secondary education, employment, crisis/complex care)
  - Lack of understanding about support needs across autism diversity and ancillary challenges (e.g., mental health, sensory considerations)
- Services often based in ‘deficit’ orientation

## **Complex Needs: Inadequate Service Response**

“[The service provider] said ‘well just call the police and they’ll take her out of the house.’ I said that would be the last thing [that should be done]. I would never... have the cops take her on a mental health warrant.... I knew that [name of individual] would kill herself if I had done that, and so that was horrible lack of support. Complete lack of understanding of autism, combined with mental health issues... just take her, grab her and put her, you know, drag her to the clinic.”

## **Insufficient Availability, Scope and Accountability**

- Insufficient follow up on individualized goals
- Rigidity (e.g. access restrictions based on IQ, age and/or level of functioning)
- Barriers: Lengthy wait times, insufficient service duration, limited funding, and inaccessibility (e.g., inconvenient or distant locations)
- Cross-sectoral support needed: financial management, social skills, behavioral supports, guardianship, housing, peer engagement, post-secondary education, employment
- Broader issues: Low service provider remuneration limiting skills and retention; funding

## Advancing Capacity: Service Provider Competencies

- Recommended supports
  - Knowledge: Transition information (e.g., knowing what to do to prepare for transition)
  - Tangible Help: Practical assistance (e.g., form completion, financial management and planning, funding)
  - Emotional Support: Guidance (e.g., listening, counselling)
  - Navigational Assistance (e.g., learning about and accessing services)
  - Training: Skill development (e.g., work skills, social skills, self-motivation, self-management)

*“We had a [disability services] family support worker who walked me through it a year ahead of time, and who gave me the list of ‘this is what you have to do in this order’ and it hugely helped. I just ticked off the boxes as I did them. There was a lot to get organized, but I was able to do it because I just gave myself a full year doing it”.*

- Organizations in the community (e.g., libraries, transportation systems, employers) gradually developing more inclusive spaces, programs and policies

## Areas for Capacity Building

### **MICRO (Individual and Family Support)**

- Person-centeredness, marked by acceptance, flexibility, and targeting needs
- Heightened expectations and support for adult achievement (e.g., career/PSE)
- Peer mentorship
- Support for parents to the role of a ‘social or life coach’ versus ‘care provider’

### **MEZZO (Program/Personnel development)**

- Capacity development in residential and community support
- Training
- Stronger relationships across diverse stakeholder groups/sectors

### **MACRO (Policy)**

- Increased funding, with targeted programming
- Autistic voice in service planning/priority setting

*“What do... individuals want to see in their life to make it happier and more successful in their viewpoint – not what we consider to be more successful, but what they are actively looking for (in) a meaningful life.”*





## Challenges in Post-Secondary Education

(Adreon & Durocher, 2007 ; Ames et al, 2016; Capozzi et al, 2019; Hotez et al, 2018)

- Self-advocacy
- Self-regulation
- Anxiety
- Social relationships
- Communication
- Academic functioning
- Confounding demands: personal, academic and campus life



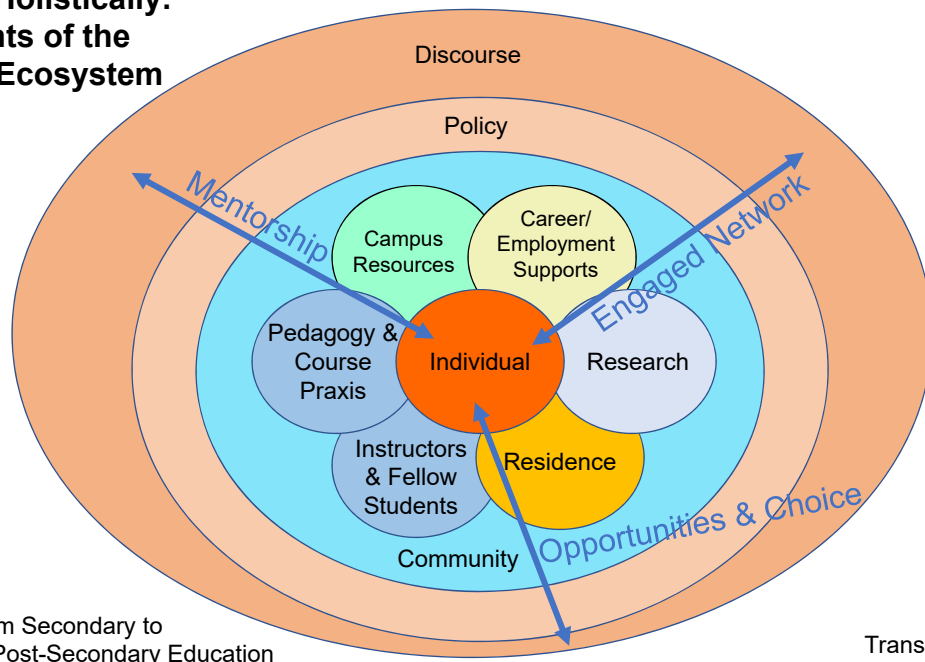
## Moving Forward in PSE

(Nelson, Brown, Nicholas, Di Rezze, et al, in review)

- Access to needed services (e.g., diagnosis, mental health)
- Peer mentorship
  
- Campus capacity building
  - Design (e.g., sensory friendly spaces, including classrooms)
    - Intentional stigma reduction
    - Training
  
- Orientation to strengths and student experience
- Supportive policy framework (e.g., EDIA, services not dependent on diagnosis disclosure, funding)



### Thinking Holistically: Elements of the Campus Ecosystem



Transition from Secondary to and through Post-Secondary Education

Transition to Career



### **Mother of an Autistic Adult...**

“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.”

## Work-related Anxiety

“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.”

## Challenges in Employment (Nicholas et al, 2018)

### EMOTIONAL/PSYCHOLOGICAL CHALLENGES

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

### FOCUS/CONCENTRATION

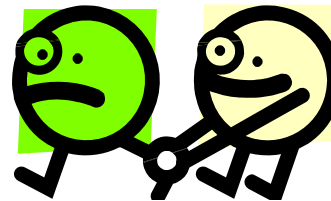
- “can’t think about doing four things at once... can focus on one”
- Varying challenges: study for hours & see patterns, but can’t remember

### ENVIRONMENTAL/PROCESSING

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

### SOCIAL/RELATIONAL

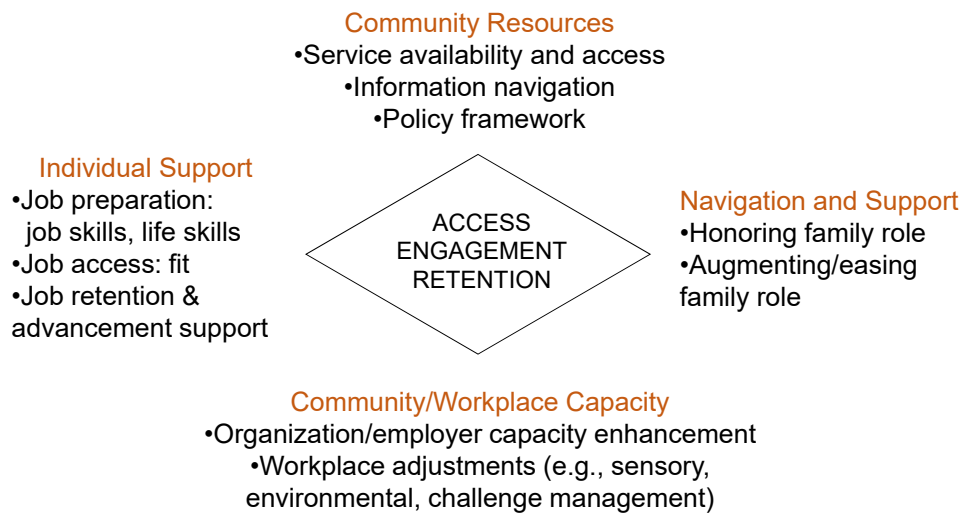
- colleagues/supervisors
- others not direct
- “too honest”
- direct communication viewed as blunt
- difficulty with strangers



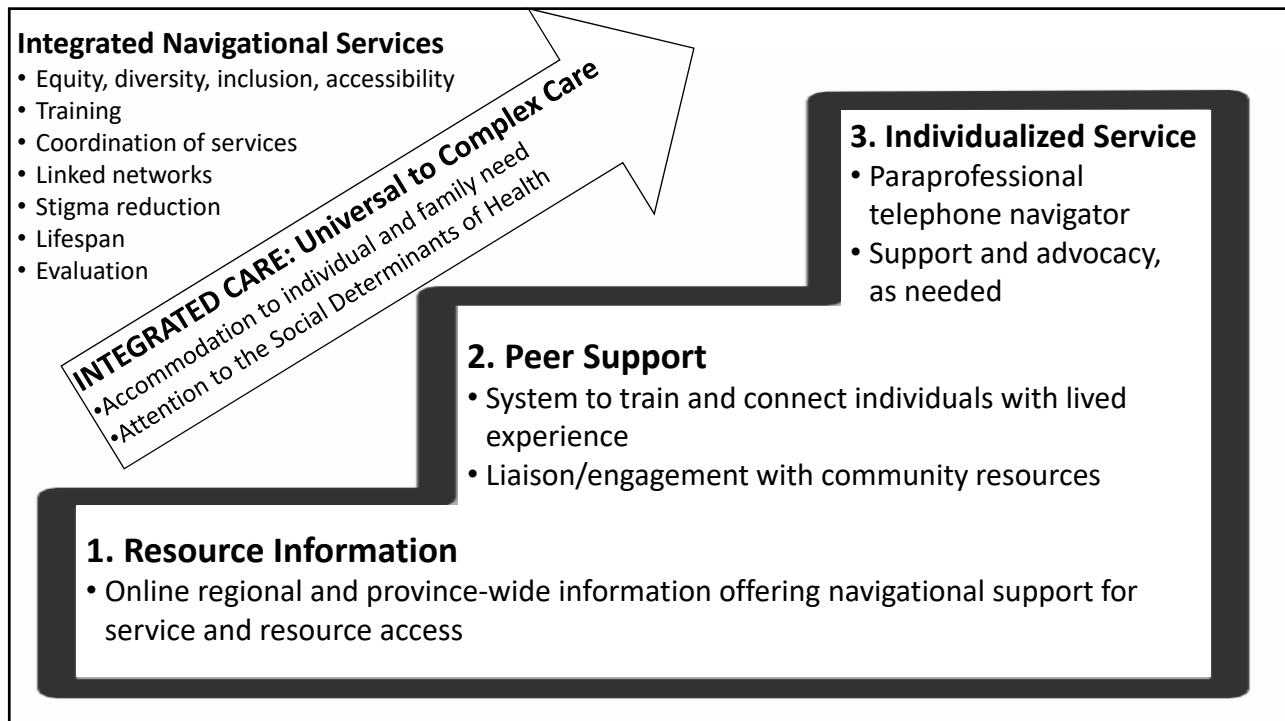
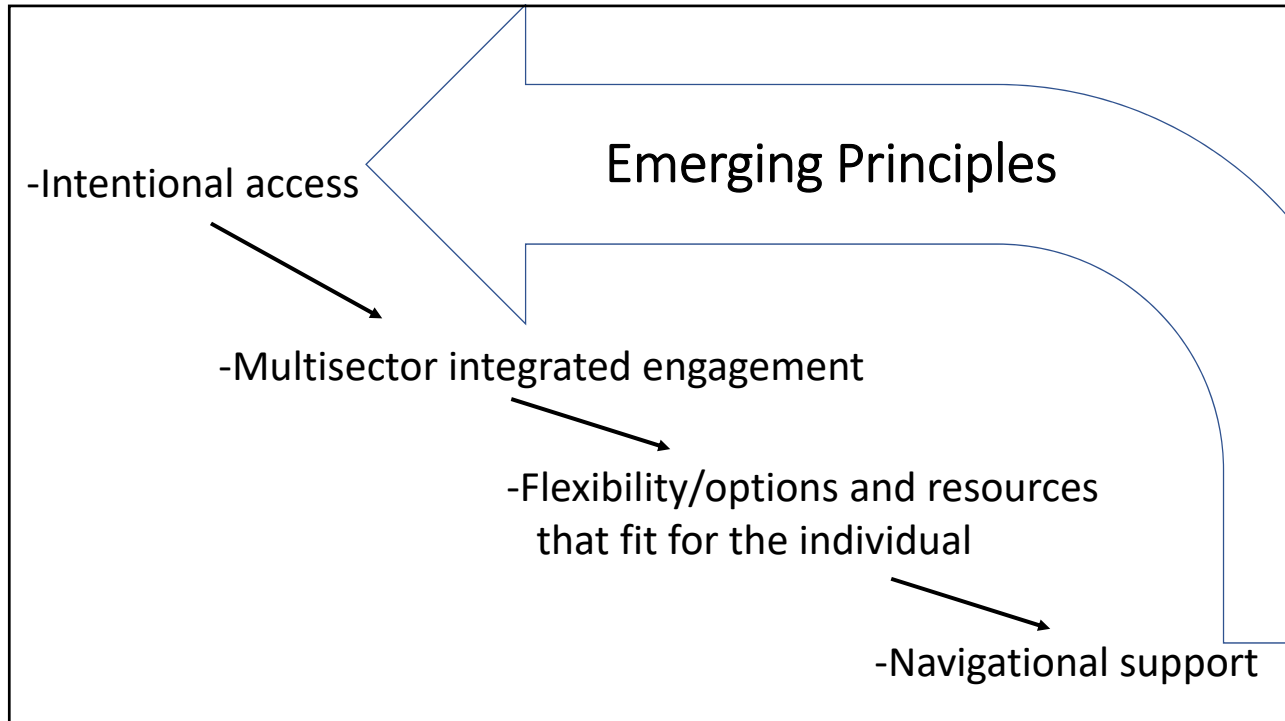


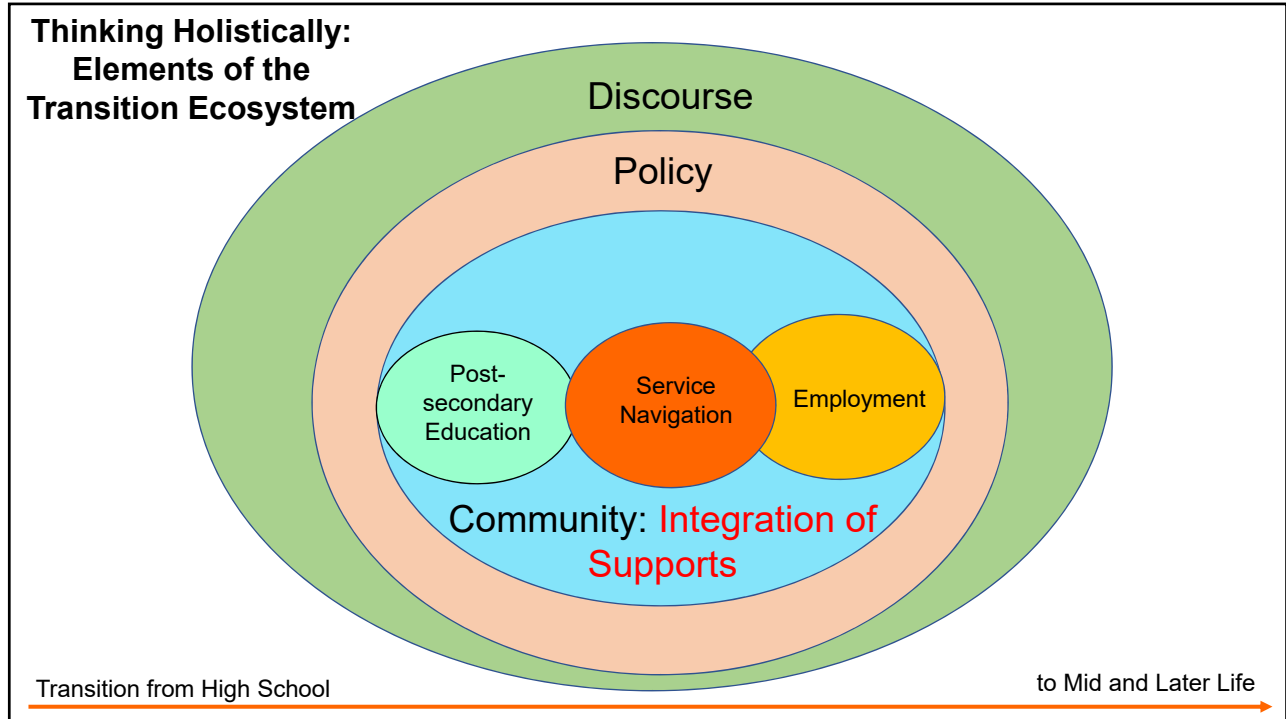


## Ecosystem Components: Employment



Adapted from Nicholas et al, 2018





**Transition to Adulthood: Discursive Context**

**See the ability**

Meet Nicholas.  
He has a girlfriend, a great career,  
and loves his life.  
He also has Down syndrome

Canadian Down Syndrome Society | Société canadienne du syndrome de Down

Lead sponsor



## Markers of Transition: Independence in Adulthood

### ***Life Course Orientation***

via fixed markers

- Independence
- External relationality
- Relational engagement/  
Social skills
- Future orientation
- Agency (e.g., health, PSE, vocation)

} Theory of  
mind

} Executive  
function

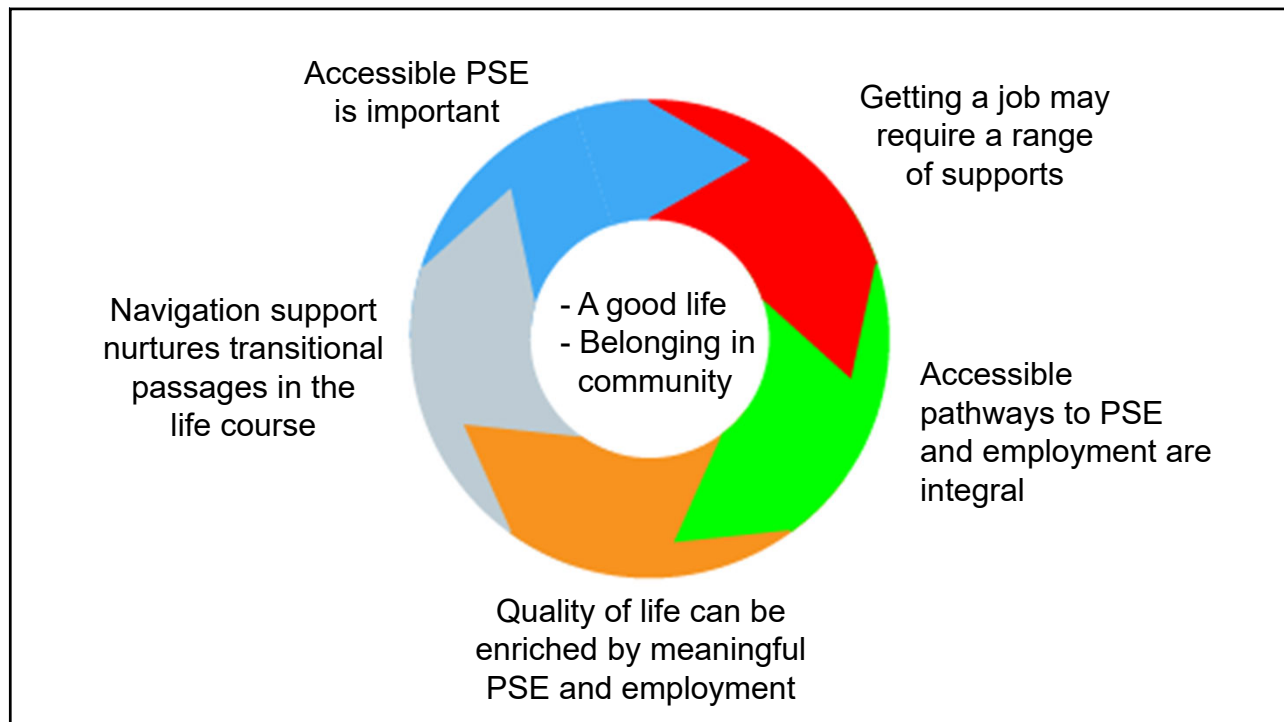
(MacCulloch, personal communication, 2012)





## Quality of Life

- “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/their life”  
(Raphael et al, 1996, p. 28)



## Implications

- Increased resources to support 'paths' to thriving
- Heightened consideration of the ecosystem
- Collective impact/action
  - Timely mobilization of evidence to action
  - Engagement of relevant systems and stakeholders
- Proactively address intersectionality and social determinants of health
- Greater focus on quality of life



## Research Recommendations

- Research partnerships in community
  - Participatory/community models
  - Data sharing for program utilization/quality improvement
  - Intervention/model-based research
  - Longitudinal and life course research
- Broad inclusion in samples (e.g., age, sex and gender, autism presentation, ecosystem sectors)
- Key engagement of lived experience
- Examination of socioecological and policy determinants
- Development of metrics and methods of assessment at individual, program and community levels

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**“Citizenship means having rights, but it also means belonging... Belonging in schools and universities, in places of work and places of worship, in politics, art and commerce: belonging in family, community, and a nation.”** Cited in Lord & Hutchison, 2007, p. 13

Dr. Catherine Frazee,  
Former Chief Commissioner  
Ontario Human Rights Commission

**Thank you**

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