



Working Together to Support Transitions

Families' Stories of Choice and Independence

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Outline

- Reflecting on Transitions
- Working Together to Support Transitions
- Families' Stories of Choice and Independence
 - Making Dreams Reality: Kelsey's Story
 - Patrick's Place
 - Lives Suspended: Saskia's Story
 - A Home of My Own: Ken's Story
- Key Principles during Transitions

Objectives



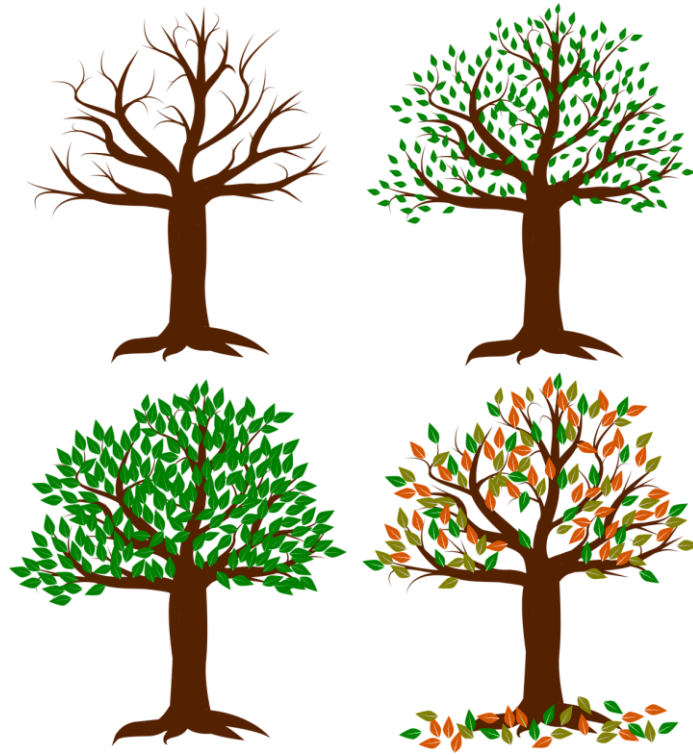
Explore families' experiences of choice and independence during transitions



Critically **reflect** on your own experiences and practices



Expand your knowledge of best practice for supporting choice and independence during transitions



Reflecting on Transitions

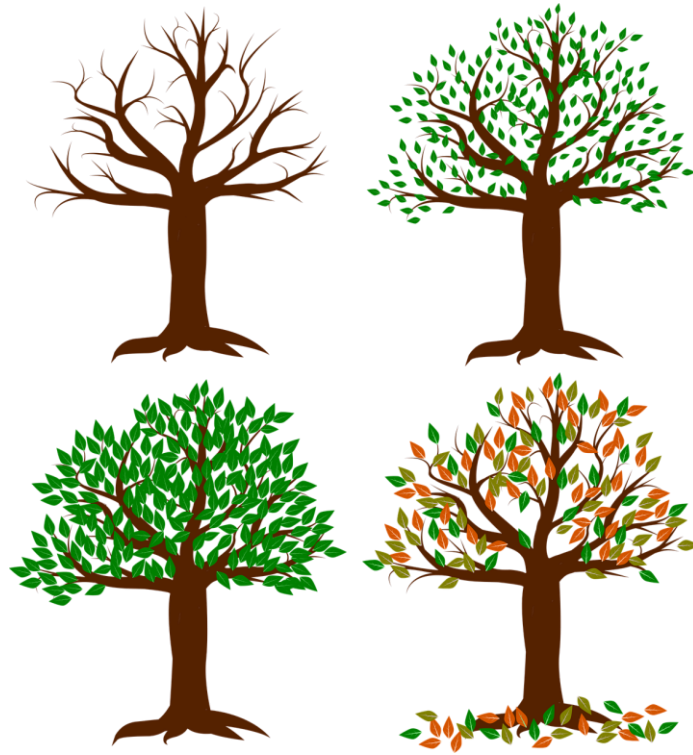
Reflecting on Transitions

- Consider a life transition you experienced:
 - Who was involved?
 - Was it expected or unexpected?
 - What choices did you have to make?
 - How did you feel?
 - What supports did you need?

Reflecting on Transitions



The only constant in life is change



Working Together to Support Transitions

Transitions for Persons with IDD and Their Families

- Persons with IDD and their families may feel stressed and unprepared when navigating transitions
 - Accessing services
 - Redefining family roles and responsibilities
 - Worrying about vulnerability to harm, social inclusion, quality of life
 - Navigating barriers to employment, education, community participation
- Amidst these challenges, persons with IDD are not always involved in making decisions that directly affect their lives

Working Together to Support Transitions

Participants

- 4 families with an adult with IDD navigating a transition

Methodology

- Longitudinal, ethnographic case studies
- Interviews and film documentation every 3 to 4 months for one year

Aim

- Gather rich qualitative data on families' experiences
- Explore formal and informal services, choices, and social inclusion during life transitions

Family Choice Making during Transitions

- What is the role of each family member in making choices for the transition?



Choice Making

Selecting options *and*
perceiving the ability to
influence the outcome

Choice-Making Opportunities

- Webber and Cobigo (2014) identified four components of effective choice-making opportunities:
 1. Frequent developmentally appropriate opportunities to make routine choices (e.g., meals, clothing) and life choices (e.g., vocational pursuits, service providers)
 2. A range of suitable options from which to choose
 3. All relevant information about the options and enough time to process the information
 4. A supportive environment
- Parents may have difficulty providing frequent choice-making opportunities to their son or daughter with IDD (Arellano & Peralta, 2013; Carter et al., 2013)

Family Choice Making during Transitions

- What is the role of each family member in making choices for the transition?

Self-Determination

Sense of autonomy and empowerment that enables goal-directed behaviour

Self-Determination for Persons with IDD and Their Families

- Persons with IDD tend to be less self-determined than their typically developing peers (Wehmeyer & Abery, 2013)

Cognitive &
verbal ability

Environment &
choice-making
opportunities

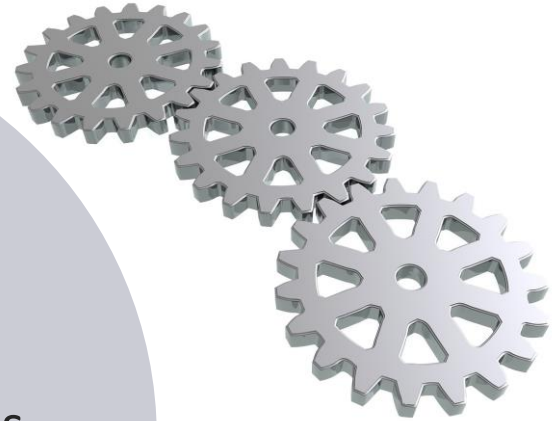
- Self-determination is a skill learned through choice-making opportunities, regardless of cognitive and verbal ability (Heller et al., 2011; Wehmeyer & Abery, 2013)

Family Choice Making during Transitions

- What is the role of each family member in making choices for the transition?

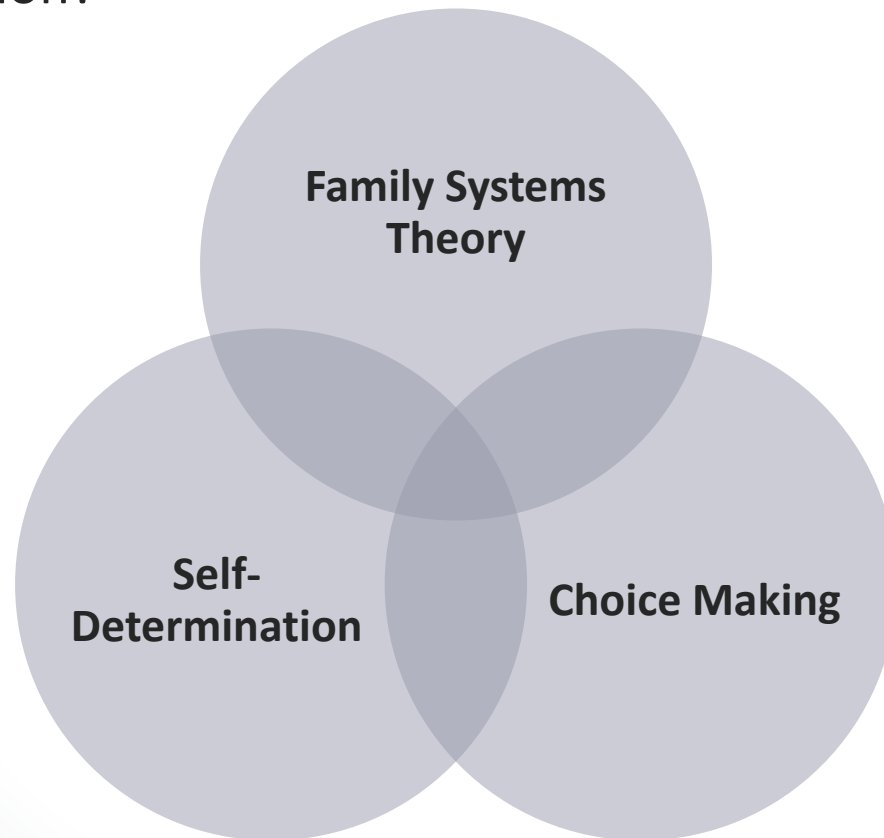
Family Systems Theory

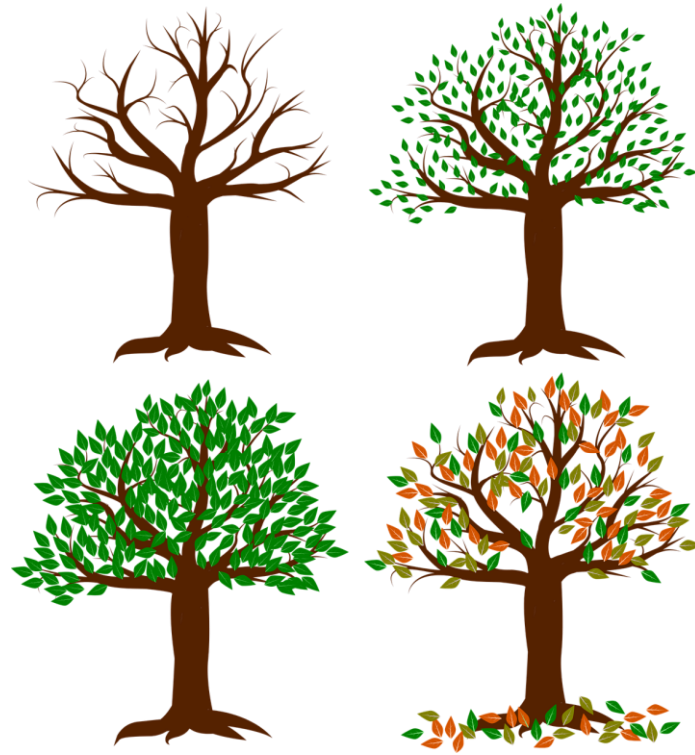
Each member of the family influences and is influenced by every other member, as well as by wider social systems



Family Choice Making during Transitions

- What is the role of each family member in making choices for the transition?





Families' Stories of Choice and Independence

Making Dreams Reality

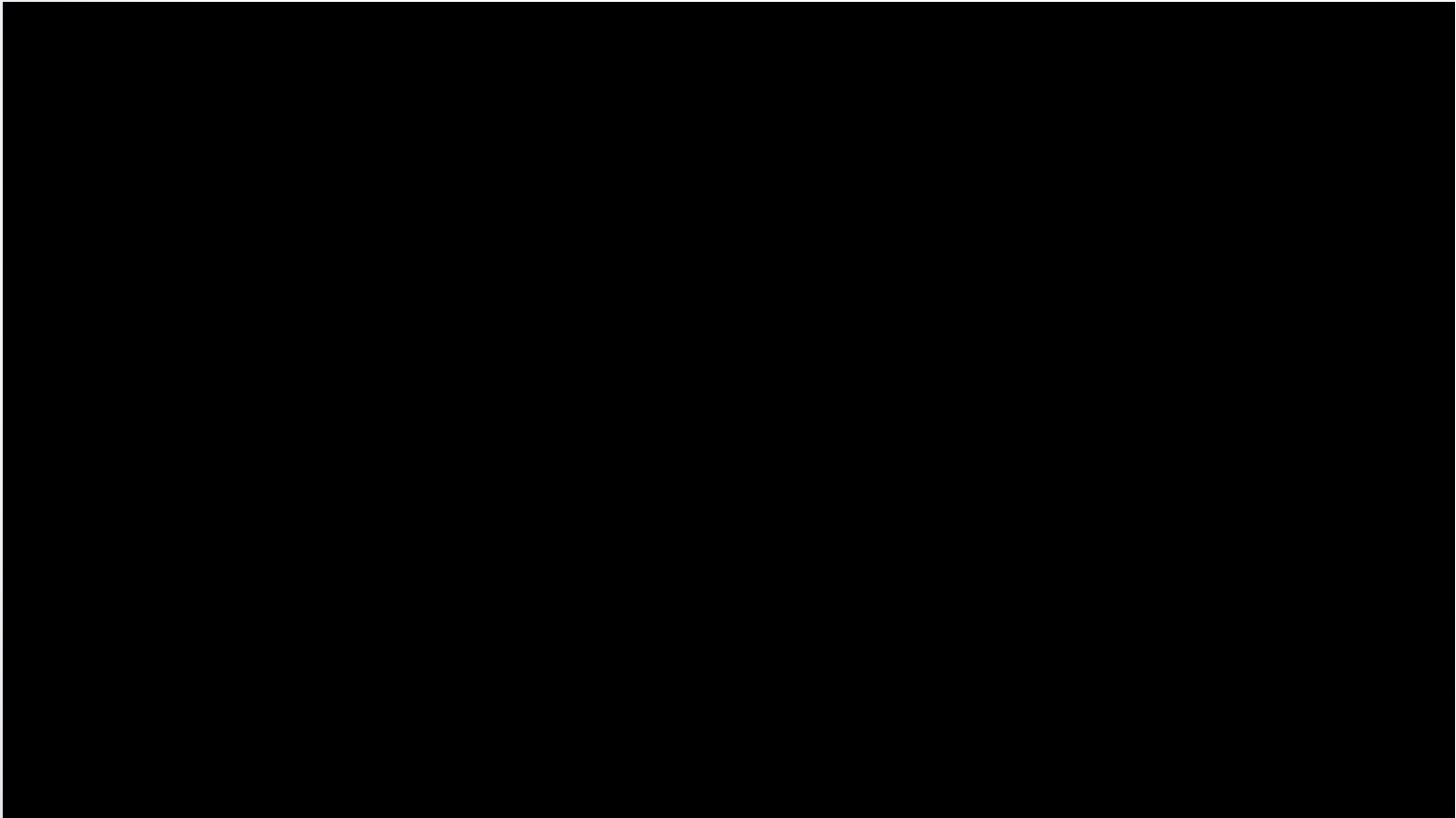


Questions to Consider

- Who is making choices for this transition?
- How can Kelsey's family help her to realize her dreams?



Making Dreams Reality: Kelsey's Story

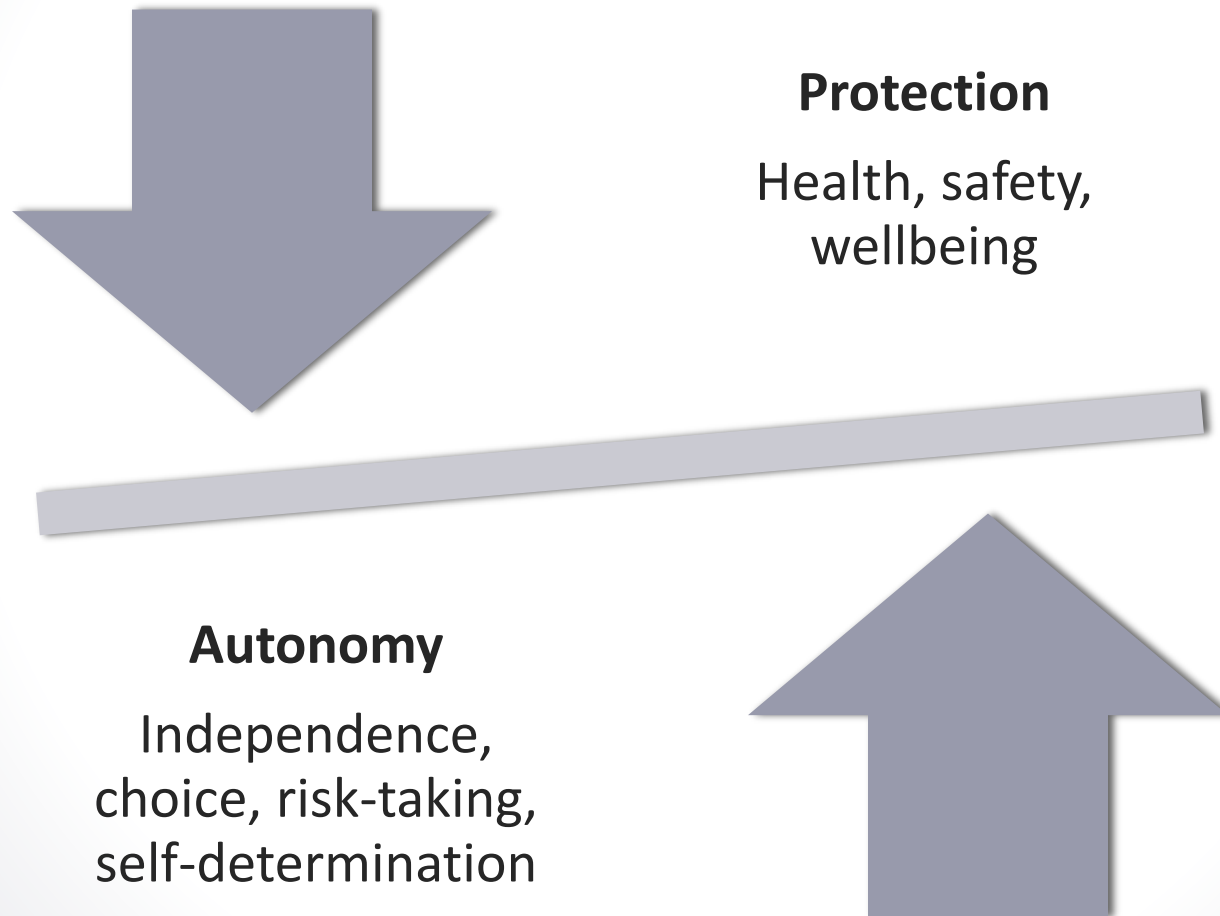


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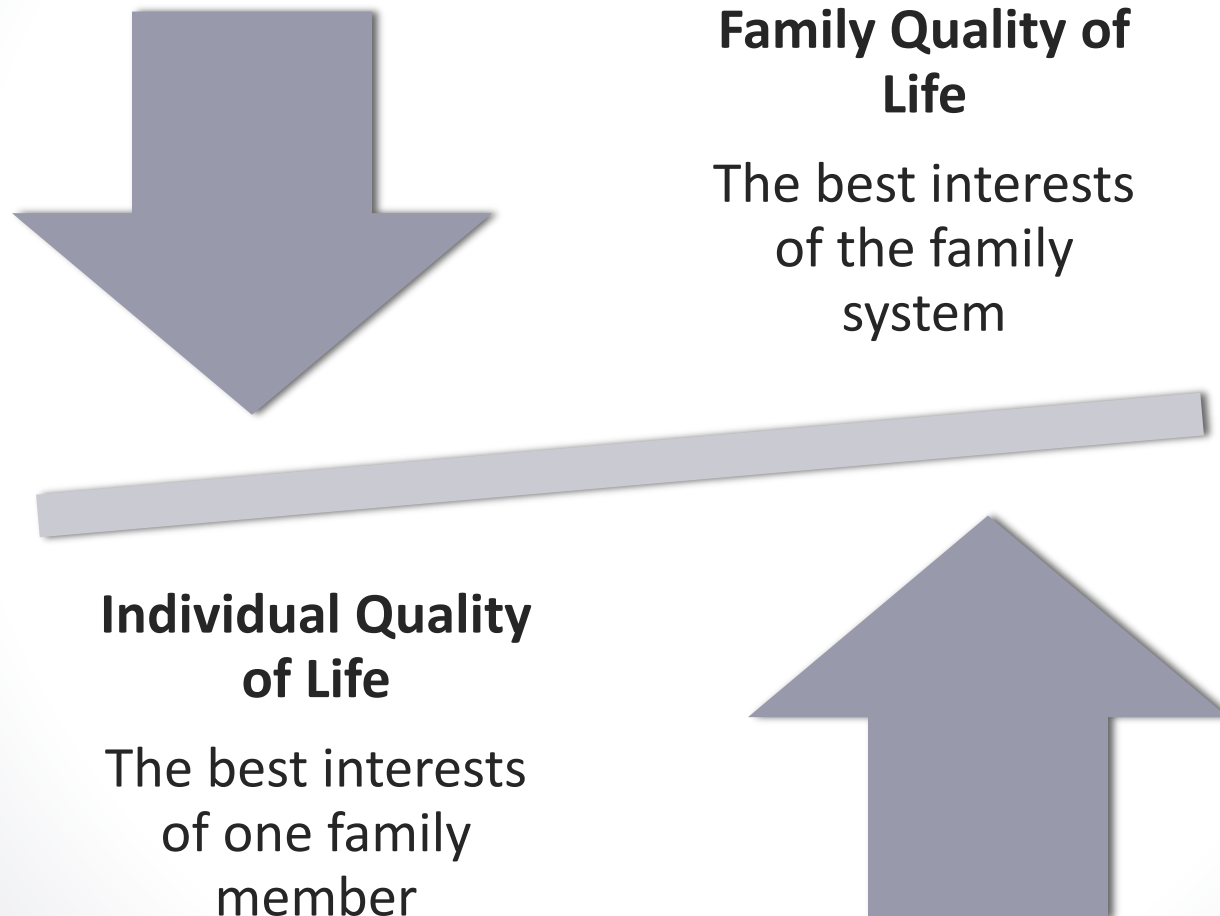
Who is making choices for this transition?

- Kelsey is expressing “big dreams”
 - e.g., University in Paris
- Her parents are helping her to reach realistic goals
 - e.g., College in Sudbury or Sault Ste. Marie
- Goal setting is an opportunity to build self-determination
- “We are trying to help match Kelsey’s wishes with what’s out there and what’s pragmatic ... What she wants but also what we think she needs to be mature and to develop as an independent adult in the community” – Parent

Finding a Balance

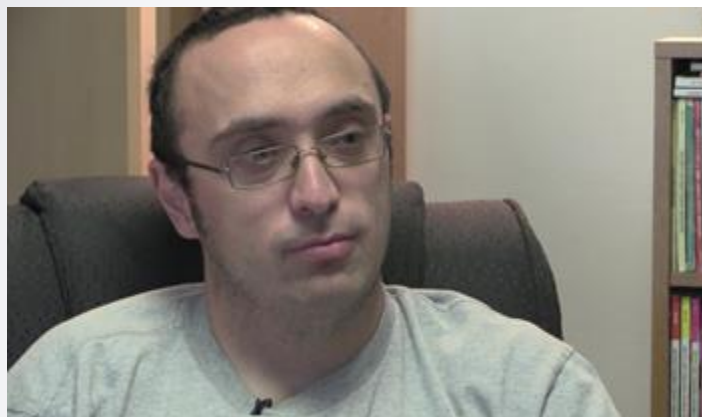


Finding a Balance

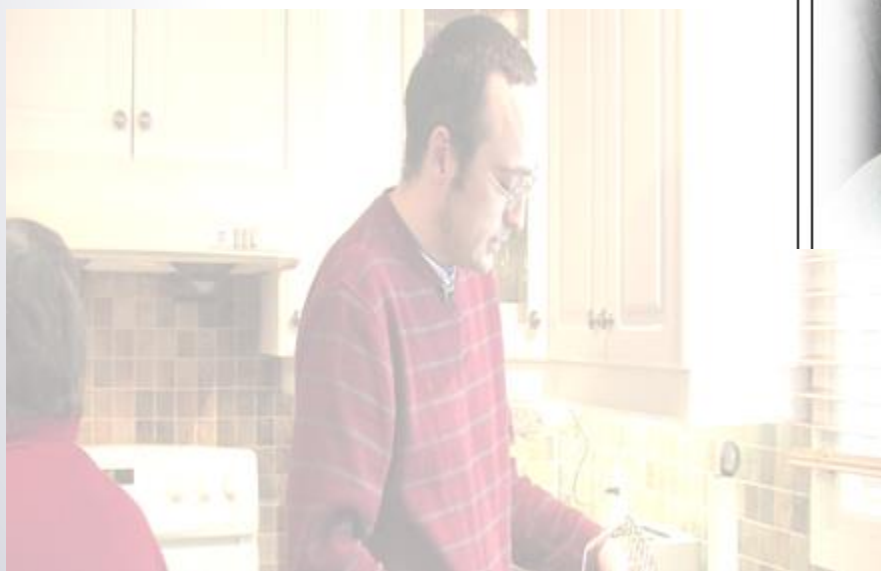


How can Kelsey's family help her to realize her dreams?

- Consider the meaning and function of these dreams
- Remember that dreams and opportunities evolve over time
- Remember that self-determination enhances quality of life and provides motivation for change
- Instead of saying “no,” harness the motivation to learn a new skill



Patrick's Place

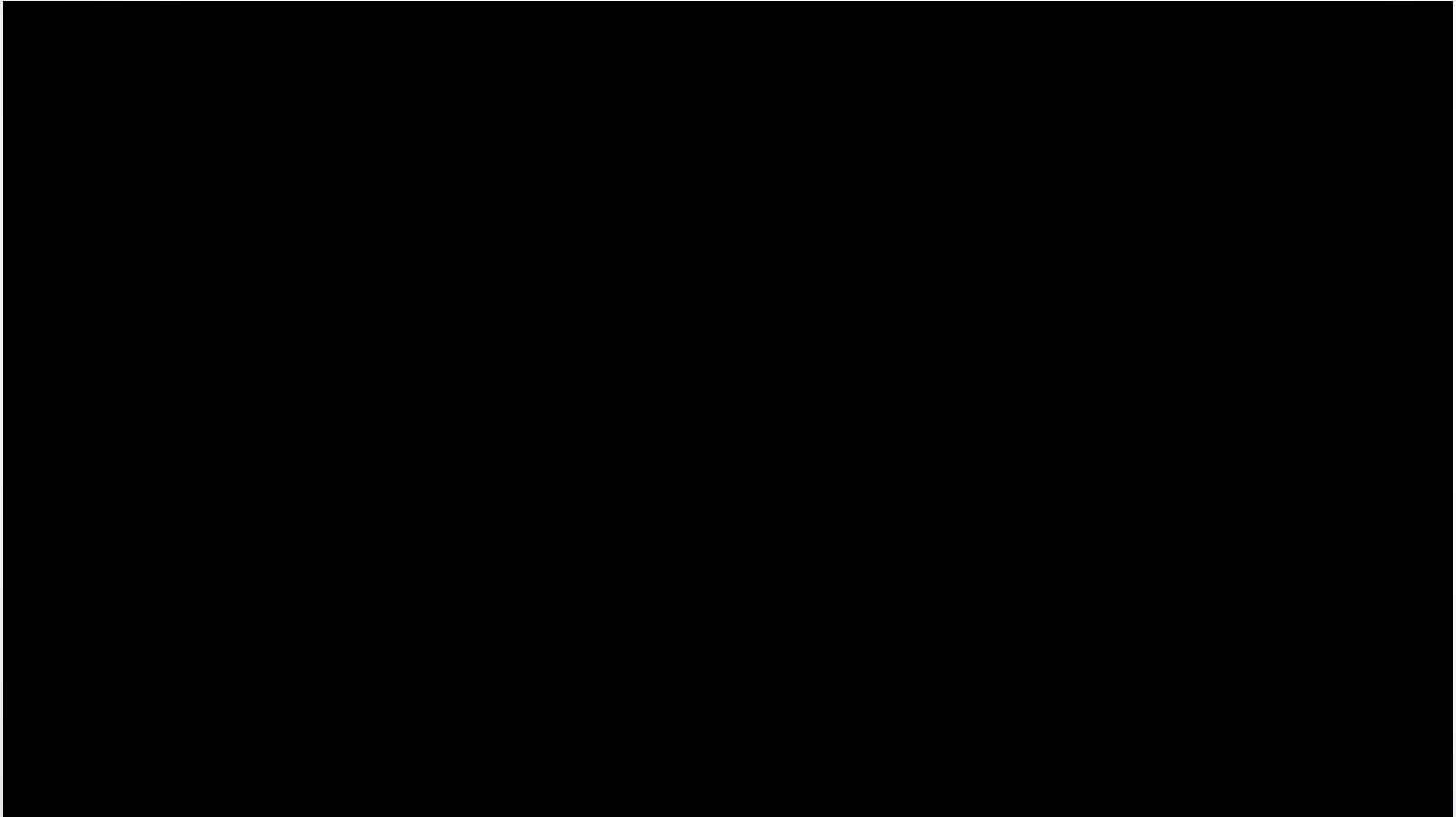


Questions to Consider

- Who is making choices for this transition?
- Whose goals are articulated?



Patrick's Place



<https://www.youtube.com/watch?v=qixfrbfk-pc>

Who is making choices for this transition?

Whose goals are articulated?

- Patrick's parents are leading the transition to encourage his independence
 - "Patrick was along for the ride." – Parent
- Patrick expressed the goal to move out, but he did not have the skills for independent living
 - "I don't want to be here when I'm 40 ... I want to be completely independent when I am 40." – Patrick
 - "First it was, 'When I'm 18, I'll move out.' And then he got 18 and, 'When I'm 21, I'll move out.' And then he says, 'For sure when you retire, I'll move out.'" – Parent
- Patrick's needs and goals interact with his parents' needs and goals in the family system

What might have happened if Patrick moved from his parents' home to his own apartment in the community?

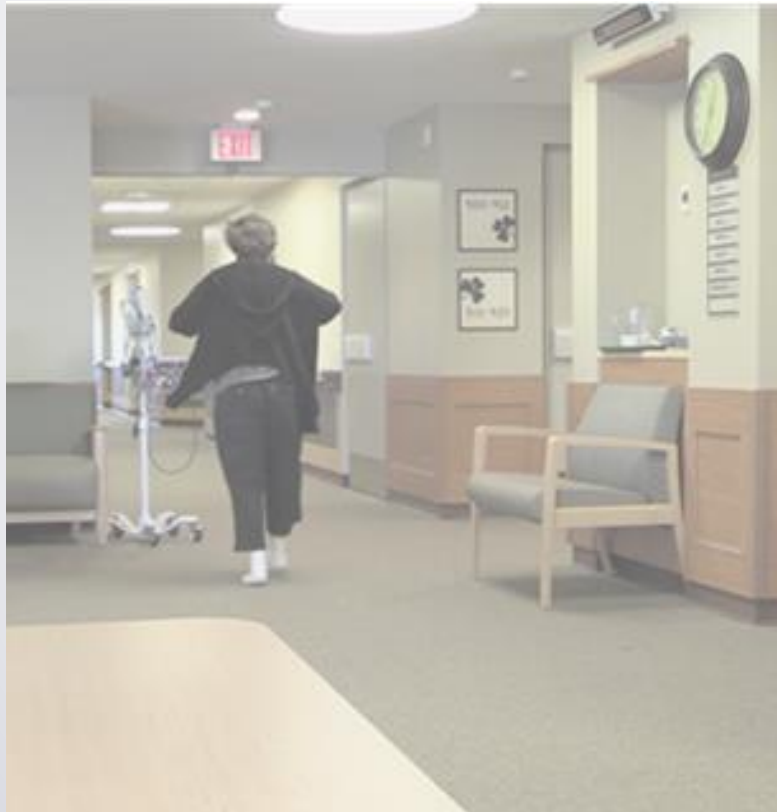
- His anxiety may have intensified, and he may have lacked the daily living skills to be successful
- Patrick's parents slowed down his transition to independent living when they realized he was not ready
- Mental health, daily living skills, and readiness for change help us to gauge an appropriate pace for a life transition
 - Optimal stress = motivating
 - Excessive stress = overwhelming
 - Monitor individual and family quality of life over time

Patrick's *New Place*

- “Pat has since moved out to a bachelor apartment ... 1 year after this taping ... We are very proud of our son, and we are confident he will get to where he wants to be.” – Parent



Lives Suspended

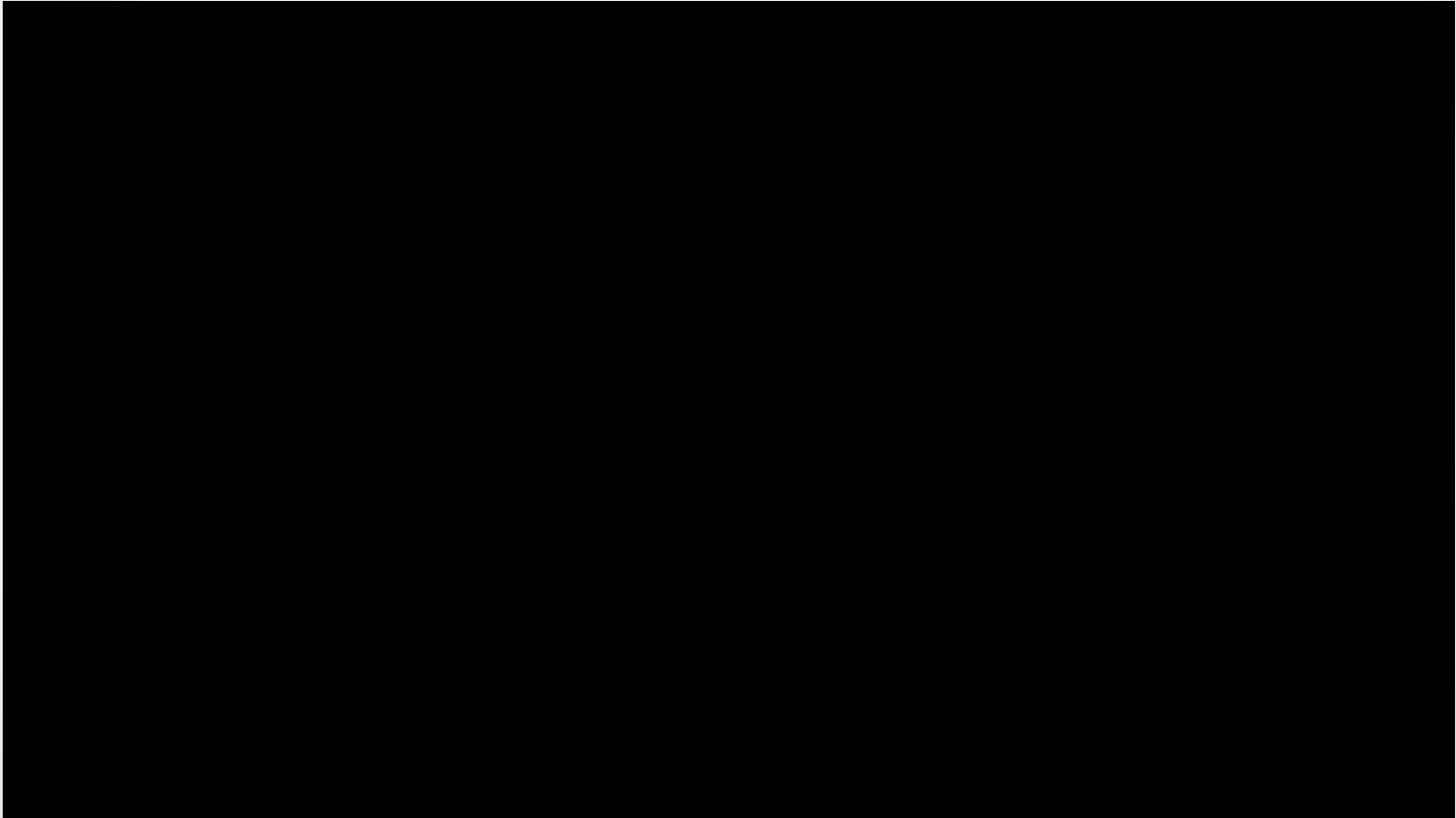


Questions to Consider

- Sometimes crises interrupt planned transitions
- How do you support and re-engage a family after a crisis?



Lives Suspended: Saskia's Story



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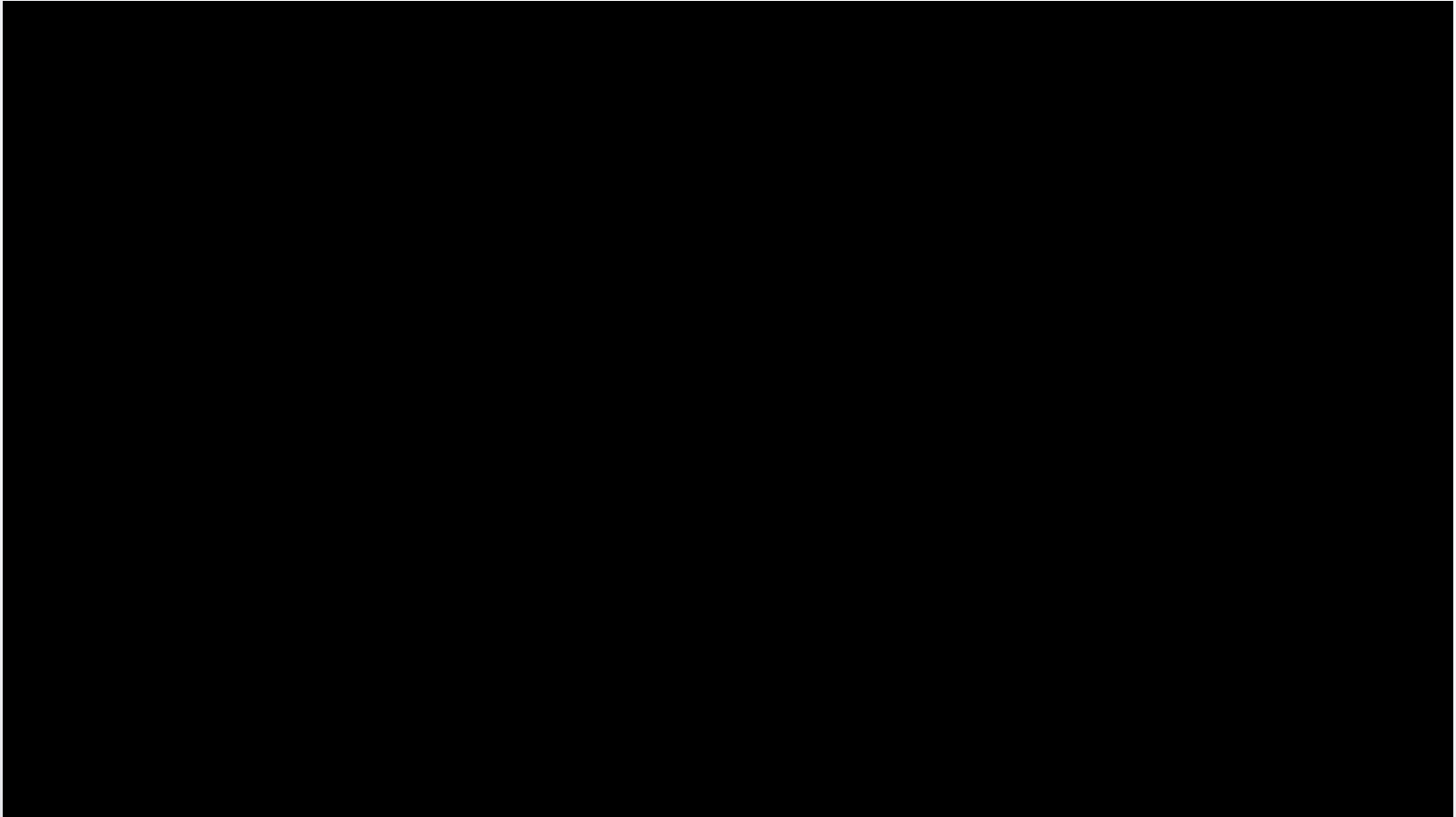
How do you support and re-engage a family after a crisis?

- Recognize the need to support the family as a system
- Listen to their stories
- Validate their emotions
- Re-assess transition plans and service needs
- Rebuild self-determination to make future decisions

A Home of My Own



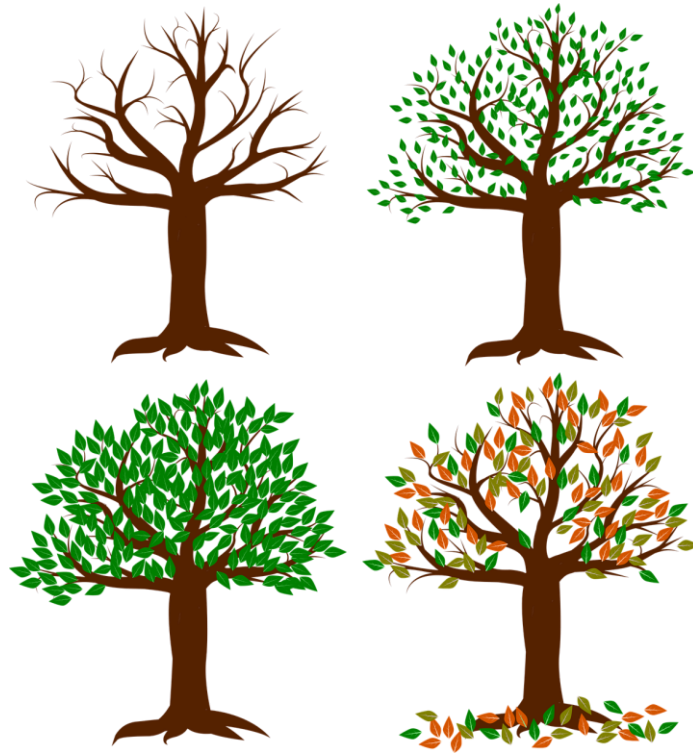
A Home of My Own: Ken's Story



<https://www.youtube.com/watch?v=VoCJiKPiFvc>

Discussion

- Families are resilient and resourceful
- Families need assistance to plan for and adjust to transitions
- Transitions are life-long processes that involve building self-determination and skills for independent living



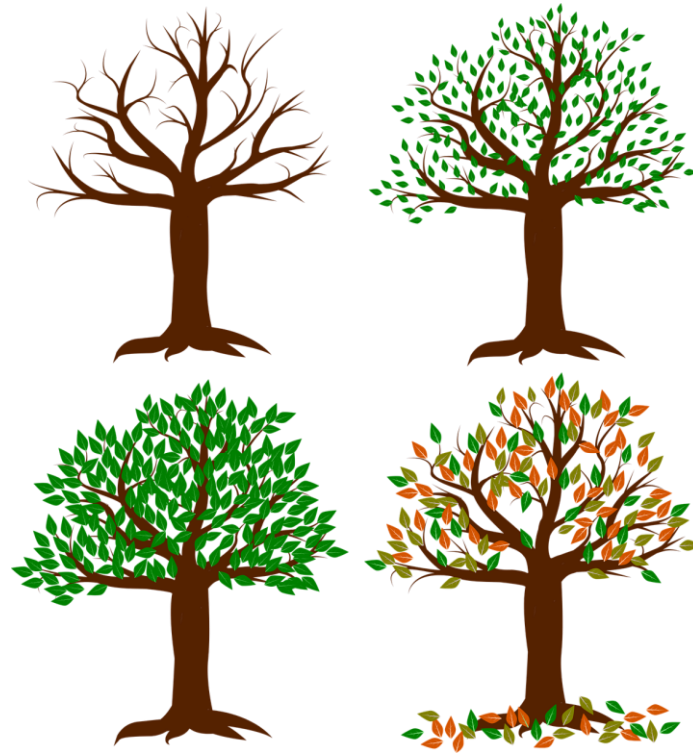
Key Principles of Self-Determination

Barriers to Self-Determination



Ways to Support Self-Determination





Key Principles of Transitions

Key Principles of Transitions

- An individual's transition is a family's transition
- Life is a series of transitions
- Autonomy and protection are a balancing act
- Goals provide motivation for new skills
- Self-determination facilitates transitions

Key Principles of Transitions

- An individual's transition is a ***Family's*** transition
- ***Life*** is a series of transitions
- ***Autonomy*** and protection are a balancing act
- ***Goals*** provide motivation for new skills
- ***Self-determination*** facilitates transitions

FLAGS

Without your flags, your transition will lag

Questions?

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