Self-determination for the rest of my life

The bridge between school transition practices and post school Quality of Life for autistic students
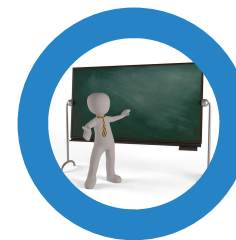
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Me as researcher

Mum

Teacher

Lecturer

Researcher

The research

Purpose of research
- To determine what transition practices support post school Quality of Life (QoL) for young autistic adults

Key terms in title
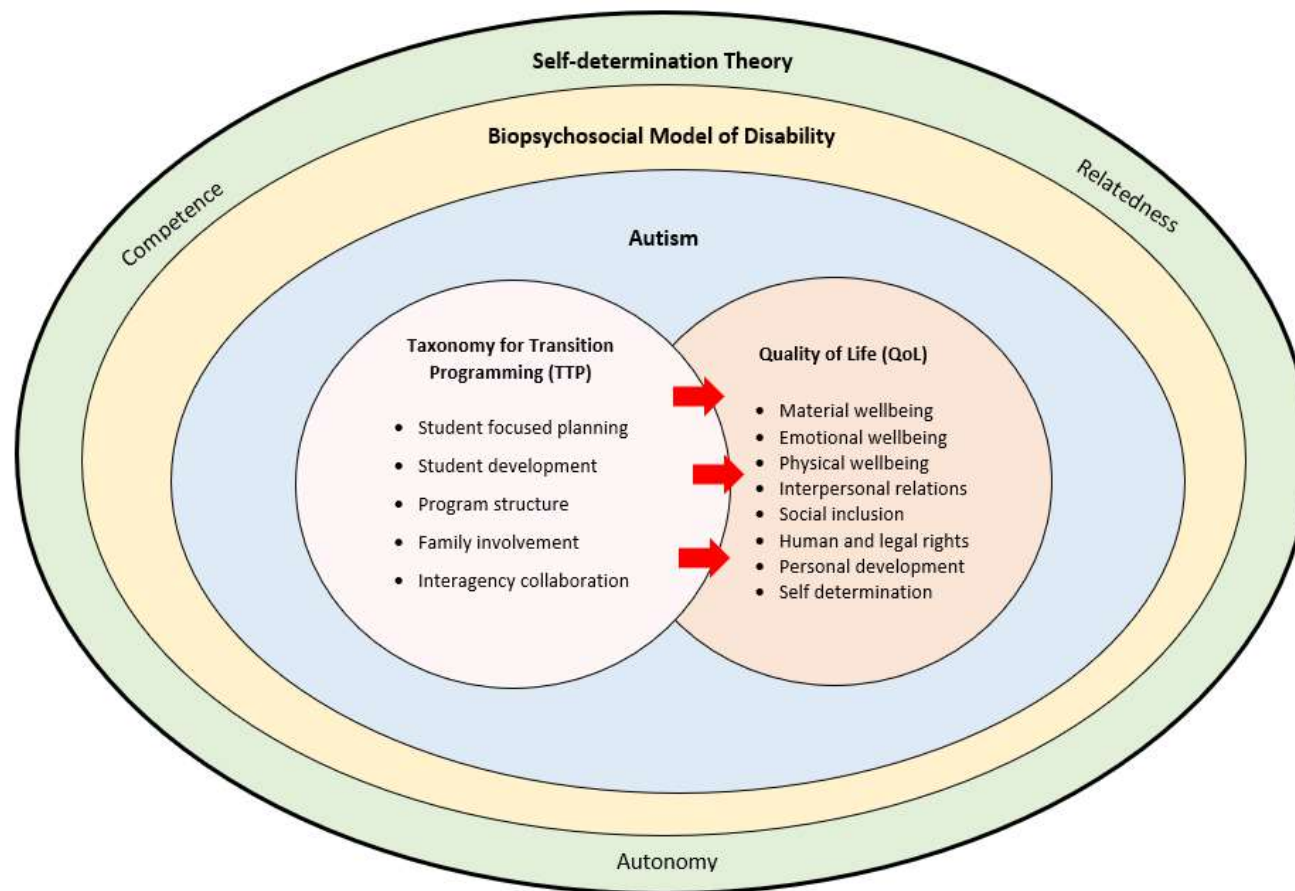- Self-determination (theory)
- Autistic adults' insights

Identity first language
- Respect for autistic people's choice

Strengths-based focus
- What we can do NOT what we cannot do

Conceptual framework

Literature Review

Poorer Quality of Life (QoL) outcomes
(Test et al., 2014; van Heijst & Geurts, 2015)

Transition practices influence QoL outcomes
(Wehman et a., 2014)

Queensland (Australia) has no mandated transition planning requirements
(O'Neill et al., 2016)

Much of the past research considered teacher's, parent's, and professional's perspectives. We need to know the perspectives of the young people themselves

Research Questions

How do young autistic adults perceive the interaction between secondary school transition practices and post school quality of life?

1. How do young autistic adults perceive their current quality of life?
2. **How and why have secondary school transition practices impacted the quality of life outcomes of young autistic adults?**
3. **What are possible enablers to the implementation of effective transition practices in secondary schools?**

Semi-structured interviews

Opportunity to meet researcher

Option to include advocate

Flexible Interview format

Flexible Place & timing

Verbal, use of visuals, photovoice

Research participants

- 9 autistic adults

- Variety of participants to capture diversity of autism and their lived experience

Gender – 5 male & 4 female

Age – 18 yrs to 38 years

Age at diagnosis – 3 yrs to adulthood

Living – 3 independent, 6 at home
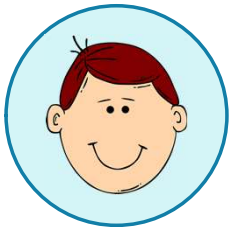
Employment – work/volunteering/studying

Support level – none/low/moderate/high

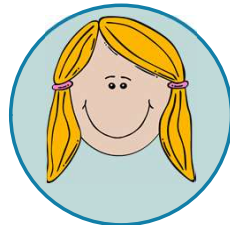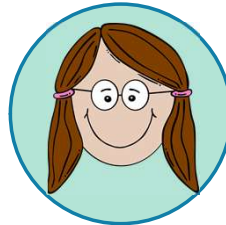Relationship status – single/partner/living with
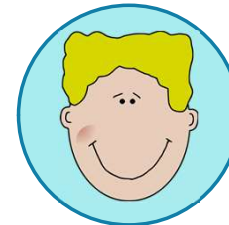
Introduction to participants

John

Anne

Helen

Eric

Tamara

Frank

Paul
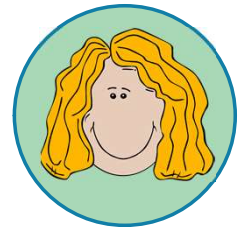
Piper
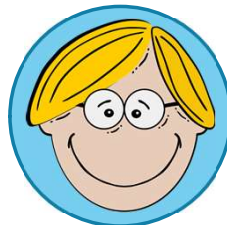
Bruce

Parents

- 8 parents
- Variety in who participated

7 mothers

1 mother & stepfather together

1 mother of 2 sisters

1 adult with no parent

Quality of Life (QoL) Outcomes

Generally good QoL outcomes

High levels of anxiety

High levels of resilience

High levels of family support

Taxonomy for Transition programming 2.0
(Kohler et al., 2016)

Student-focused planning

Student development

Family involvement

Program structures

Interagency collaboration

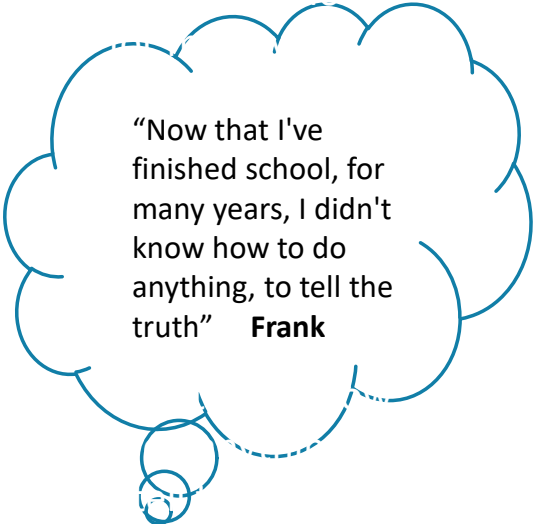# Transition practices

"I was pigeonholed into doing something that I didn't want to do. I didn't feel like I had much control over anything at school. When I did my interview in grade 10, I was saying, "Yes, I really want to do history. I want to make it a career." I was basically told that "History is a not a good career option. Why would you want to do that? It's better to go into nursing." **Anne**

Student focused planning

- Senior Education and Training (SET) plans

- One-off subject selection/ Not transition focused

- No progress review

- Not focused on **student's strengths and interests**

"There was a certain condition or direction put forth as far as what post-school options would be available", "John was given a choice of transition pathway, retail or hospitality. It was fortunate he showed an interest and strength in hospitality. If his interest had been something less common, it might not have been supported." **John's mother**
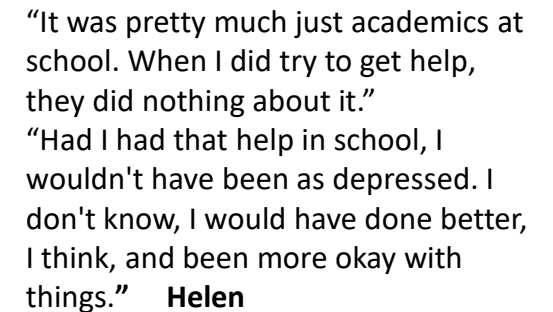
Transition practices

Student development

- Focus on academics

- Limited use of assessment

- Limited life skill development

- Limited employment skill options

- **Limited social/emotional support or strategy development**

"Now that I've finished school, for many years, I didn't know how to do anything, to tell the truth"   **Frank**

"It was pretty much just academics at school. When I did try to get help, they did nothing about it."
"Had I had that help in school, I wouldn't have been as depressed. I don't know, I would have done better, I think, and been more okay with things."   **Helen**

Transition practices

Family involvement

- Family involvement limited to one-off meetings and parent teacher communication

- Limited/no family empowerment

- Limited/no family preparation

- **Families are leading school to post school transitions**

> I would go and pick him up and he would go and volunteer on Tuesday afternoon. In school time" "Completely separate from school. They knew he was doing it, but that was because we just told them that's what we had initiated."
>
> "School didn't incorporate family initiated and driven experiences into the school program. They thought that we were doing something, and it was good and that was that."
>
> **John's mother**

> "There was nothing really planned for the future, so I planned it." **Frank's mother**
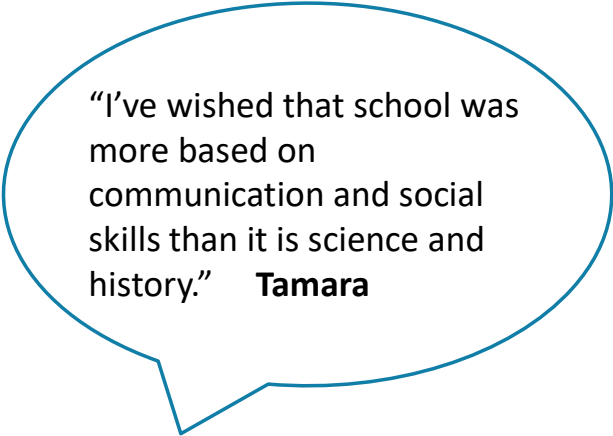
> We said to Anne, "History is something that you love. Why not go down that path? You can always change later if you really want to go into nursing, but at least start with something that you love and try and work from there."
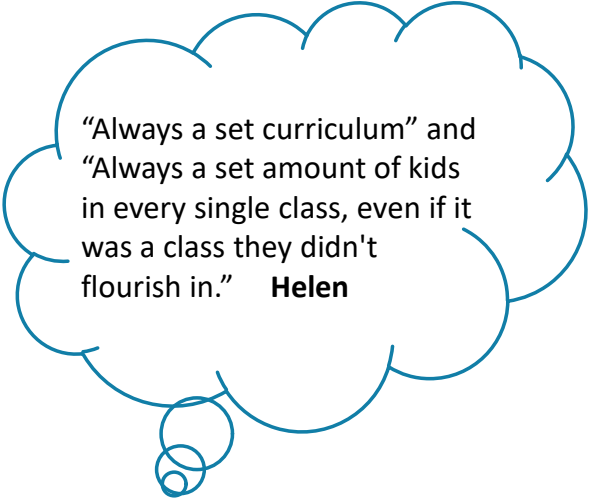> **Anne's mother**

Transition practices

Program structures

- Rigid and inflexible

- Limited policies, procedures, strategic planning or resources allocated to transition planning

- **Positive school connectedness is key**

"I've wished that school was more based on communication and social skills than it is science and history."   **Tamara**
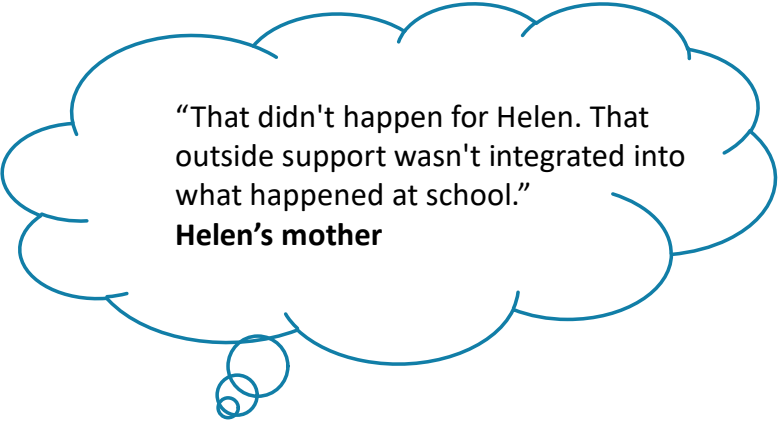
"Always a set curriculum" and "Always a set amount of kids in every single class, even if it was a class they didn't flourish in."   **Helen**

Transition practices

Interagency collaboration

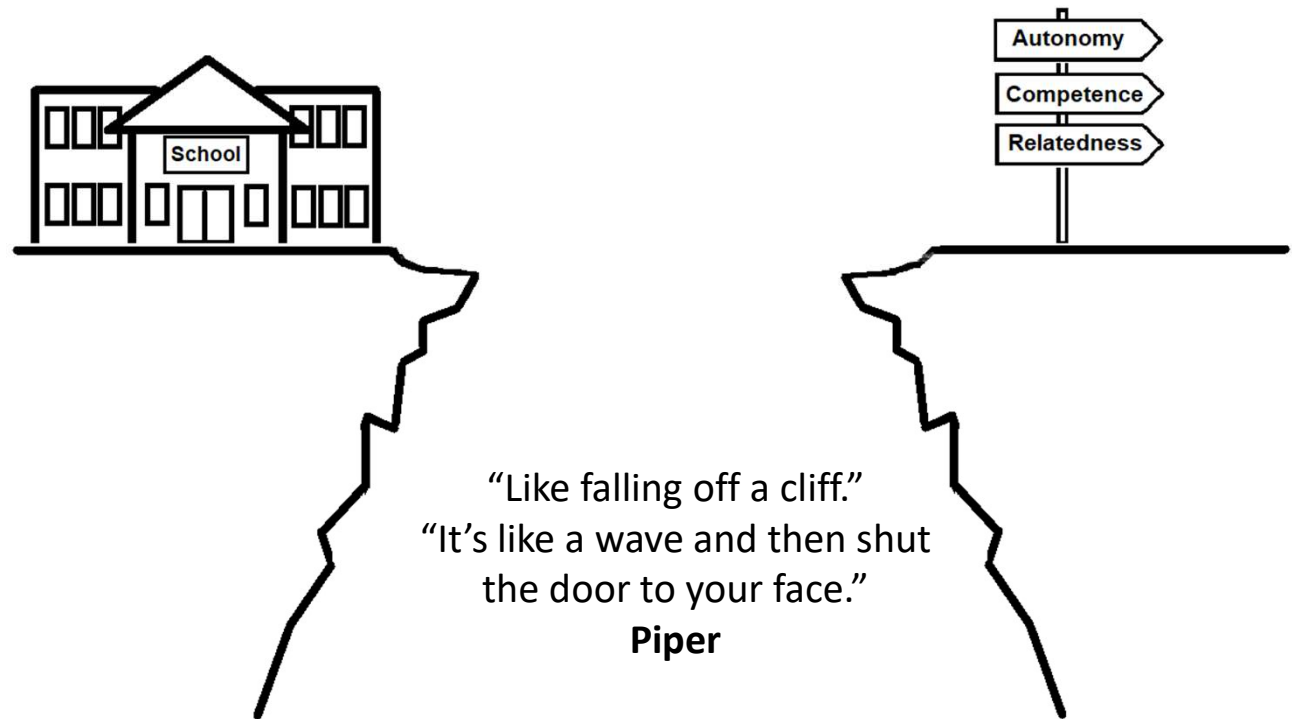- **Limited interagency collaboration regardless of post school option**

"That didn't happen for Helen. That outside support wasn't integrated into what happened at school."
Helen's mother

"We thought we would sign a form saying we give the university access to all this information and that … that gets passed on from the school. There was no communication. So, there was no documentation sent to the University, there was no meeting set up. We kind of thought, wrongly … I assumed we would see this smooth transition, but it wasn't."
"It felt like starting again. It didn't seem to matter that we knew … like that we had done this for years … it felt like we didn't know anything."   **Piper's mum**

Current transition experiences

School

Autonomy
Competence
Relatedness

"Like falling off a cliff."
"It's like a wave and then shut the door to your face."
Piper

Enablers (bridges)

Work closely with families on school to post school transitions

Focus on student's strengths and interests

Provide social/emotional support and strategy development

Strong school connectedness

Improved Quality of Life (QoL) across all domains:

Material wellbeing

Physical wellbeing

Emotional wellbeing

Interpersonal relations

Social inclusion

Personal development
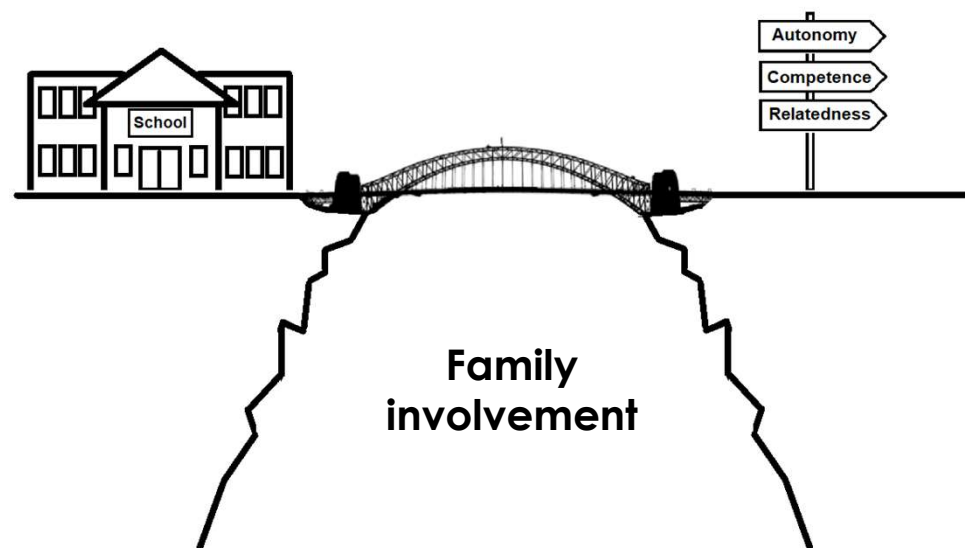
Self-determination

Human and legal rights

Key enabler – family involvement

Families are the bridge between school and post school

Schools must work to better enable

- **Family involvement**
- **Family empowerment**
- **Family preparation**

for the families of young people on the autism spectrum

Key enabler – Strengths and interests

Schools need to focus on supporting and encouraging the young person's strengths and interests during school and as part of the transition planning for post-school options

- Engaging with **strengths & interests increases QoL**

- It allows for **higher levels of autonomy, competence, and relatedness**

- Therefore, **increases self-determination**

Autonomy

Competence

Relatedness

School

Strengths & Interests
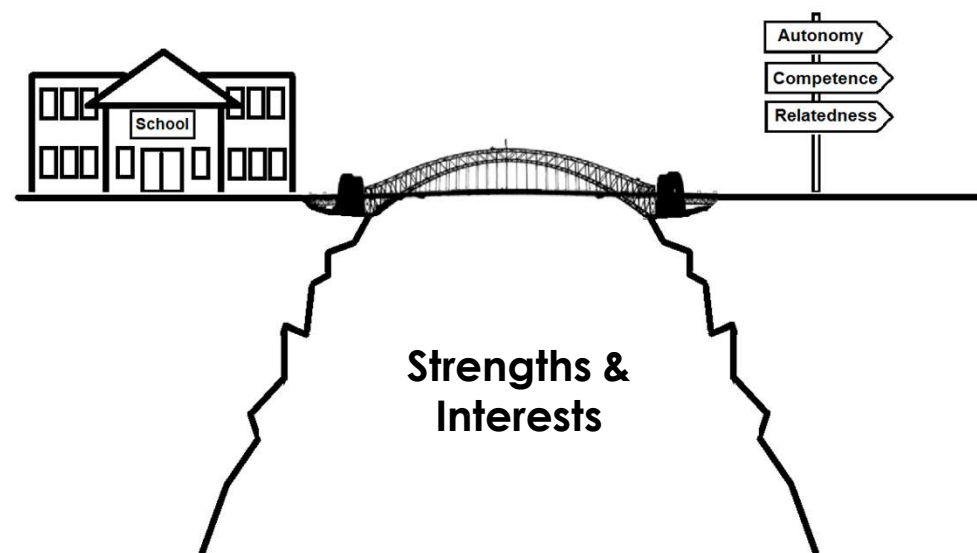
Key enabler – Social/emotional support

Schools need to focus on providing social/emotional support for autistic students. This includes:

- Support on a **day-to-day level**

- Building of strategies for **long-term social/emotional wellbeing**

- **Working collaboratively** with families and outside professionals

Autonomy
Competence
Relatedness

School

Social/emotional support
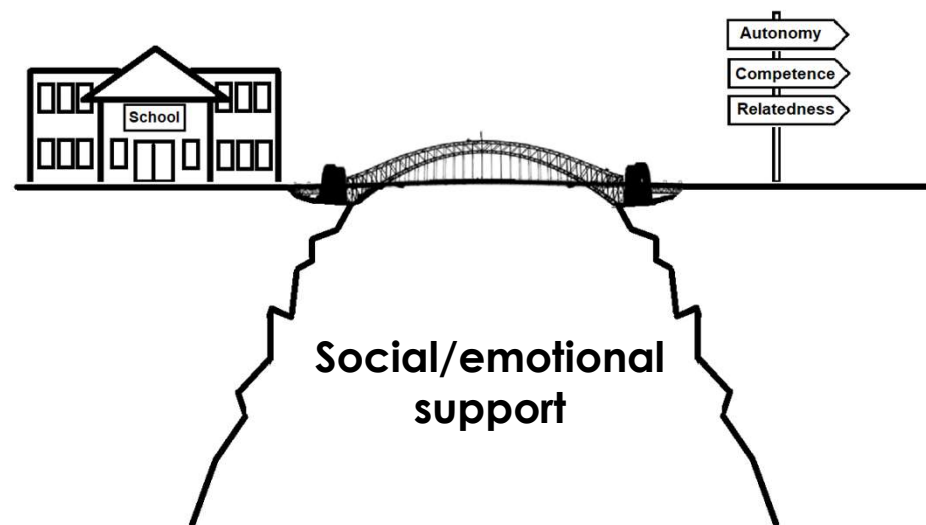
Key enabler – School connectedness

School-based relationships are critical

- **Student-teacher relationships**

- **Peer relationships**

Autistic adolescents and young adults experience a higher QoL when they have a sense of **belonging, connectedness, and believe that people understand and care**

Schools need to foster and support these relationships through **greater awareness about autism**
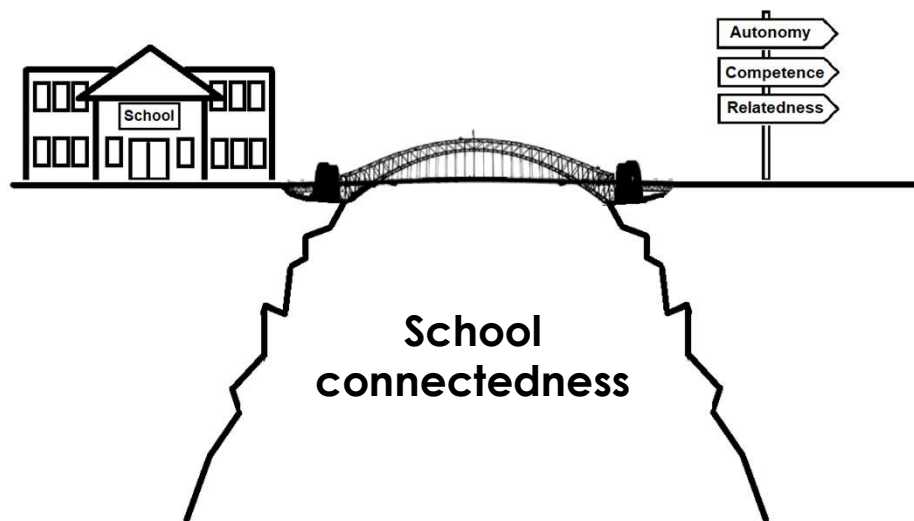
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Questions

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