



A priority setting partnership to
identify practices which promote
participation for children with a spinal
disability.



**THE UNIVERSITY
OF QUEENSLAND**
AUSTRALIA

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RESEARCH TEAM



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RESEARCH TEAM

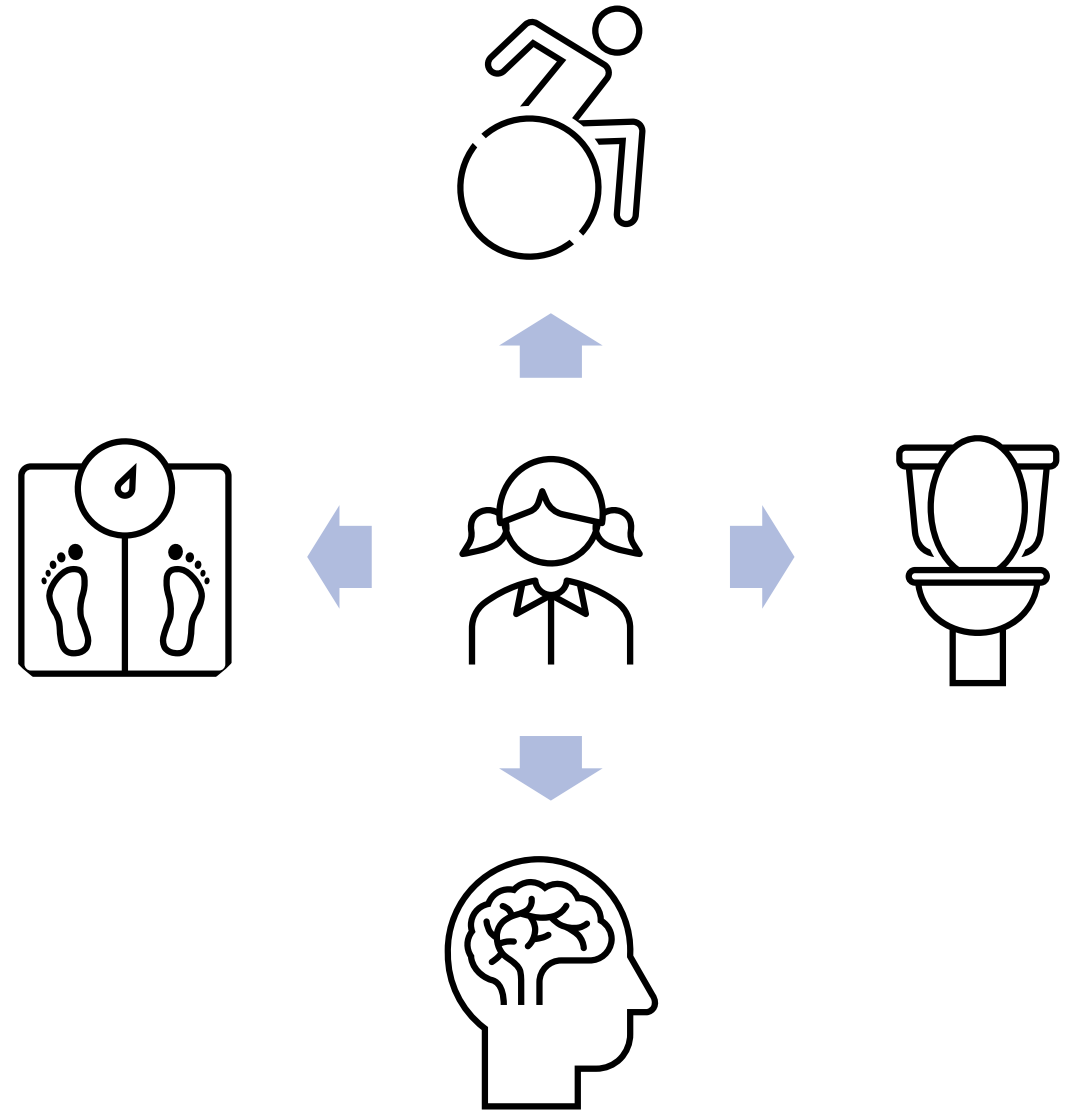
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Dr Lisa Copeland, Paediatric
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Traditionally research
has focused on
understanding spinal
disabilities and how
they present.



**Understanding bladder
and bowel function**

**Determining lesion level and motor
function**

**Body Functions
& Structure**

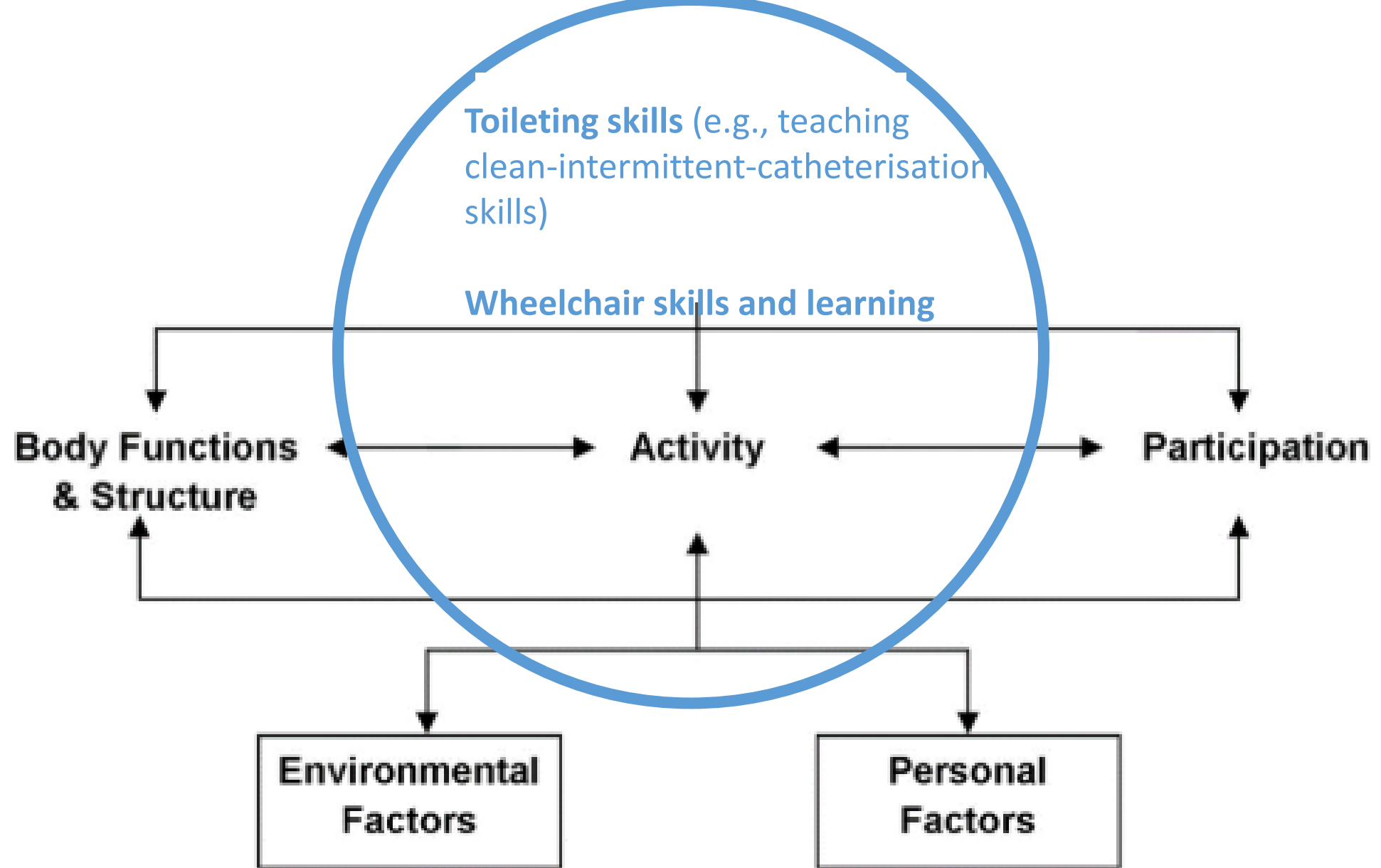
Health Condition
(disorder or disease)

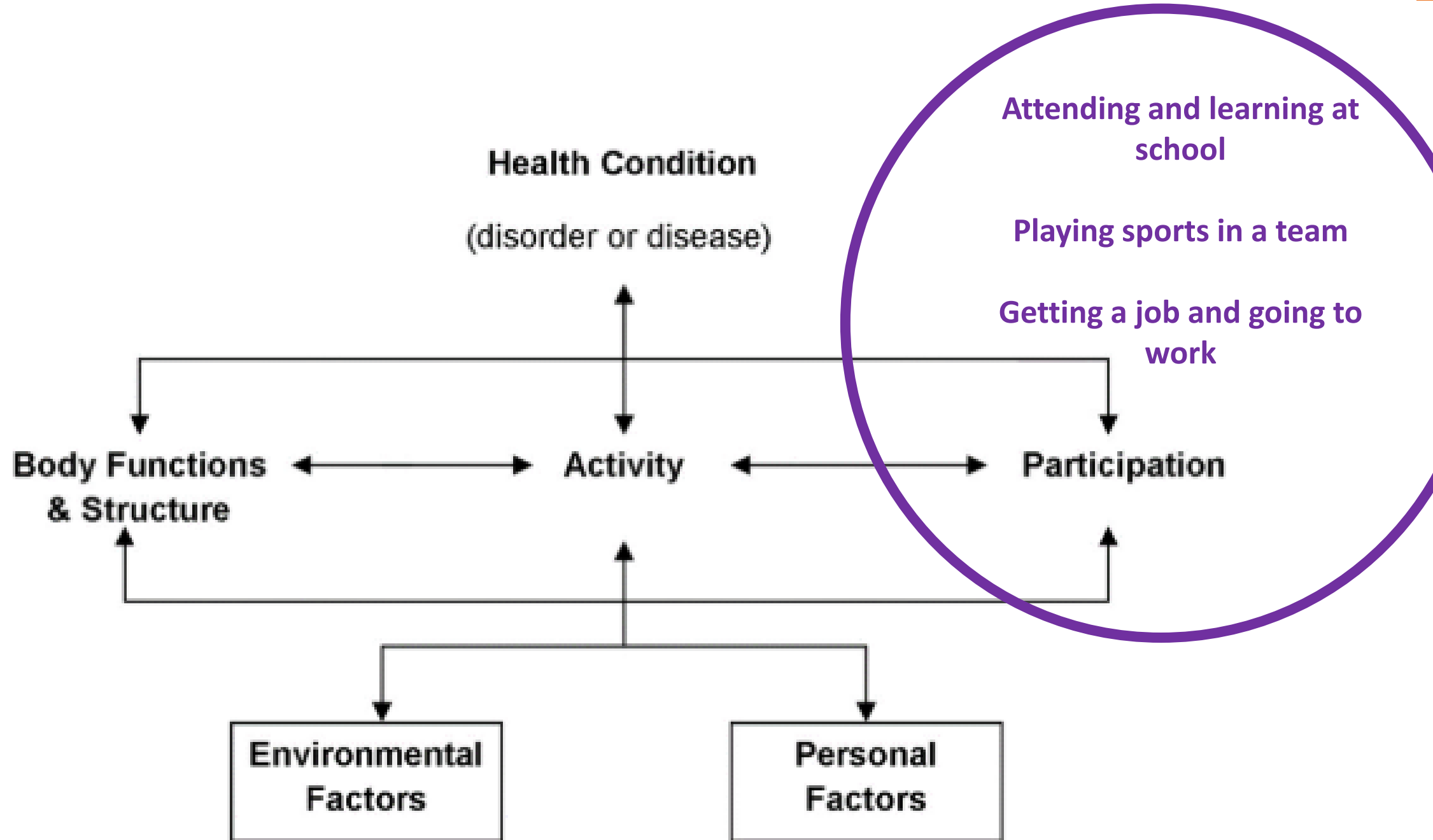
Activity

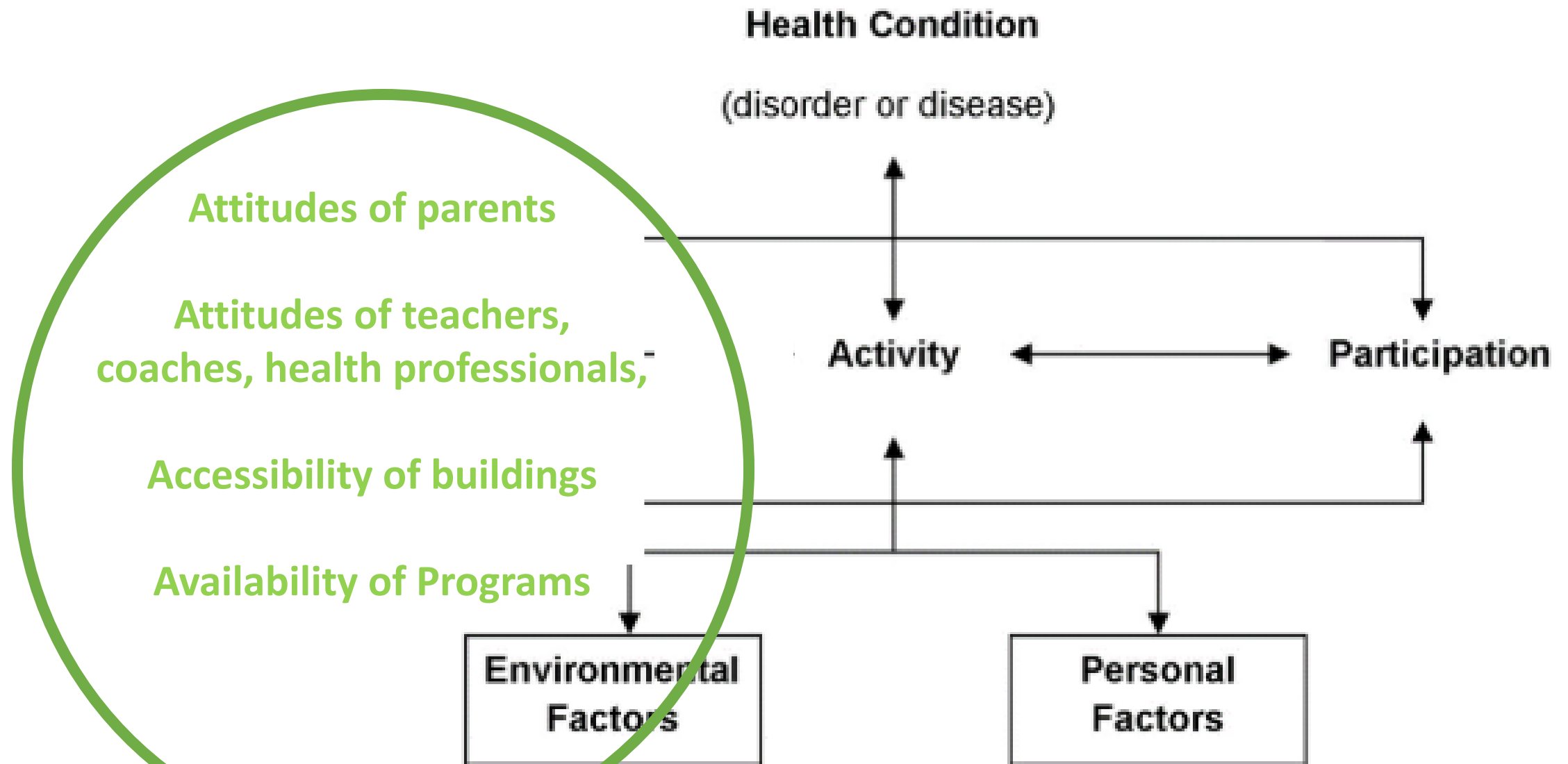
Participation

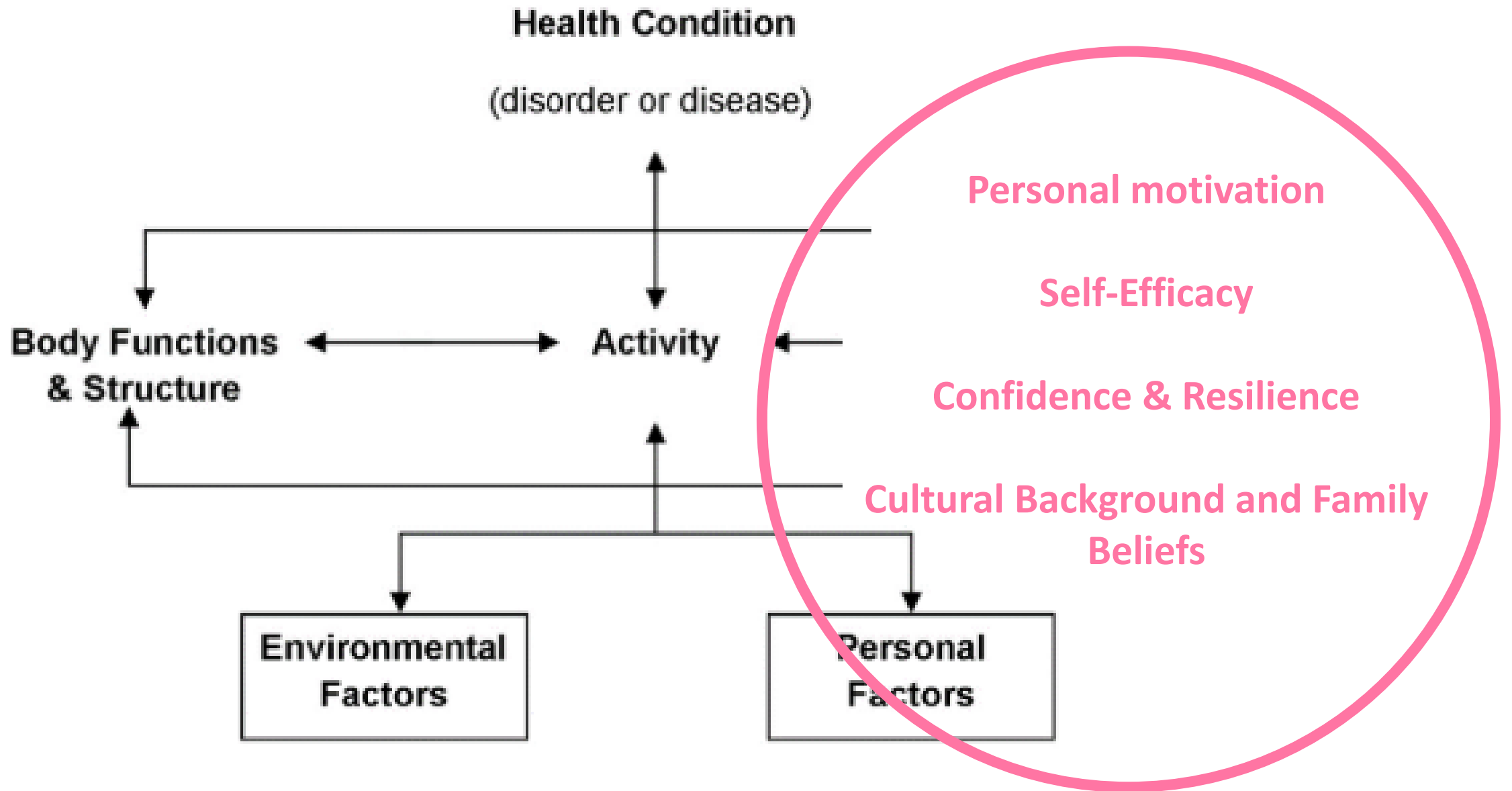
**Environmental
Factors**

**Personal
Factors**











So we asked them...

What are the health
professional practices that
promote participation for
children with a spinal disability?

Project Overview:

Part 1: Small-group discussions

Steering Group members engaged in 3 small group discussions to identify practices which promote participation.



Part 2: Survey

Survey participants rated the importance of the practices identified by the steering committee.

Participants were also invited to comment on the practices and add anything they thought was missing.



Part 3: Consensus meeting

Consumer partners come together to determine next steps, based on the practices identified in the priority setting partnership

Steering Group Members:



8 Health Professionals

PT, OT, SLP,
Neuropsych, SW, Paed,
Nursing) from both
hospital and community
settings.



5 Parents of young people aged 0-18 years old

City and Regional
Locations

**Missing: Dad's
perspectives**



4 Young People who have a spinal disability

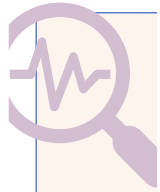
Ages 12-25 years

2 Females

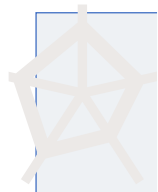
2 Males

3 Wheelchair Users

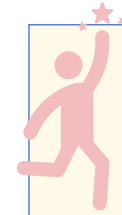
Young People's Perspectives



Set goals together that fit into/help me with daily life.



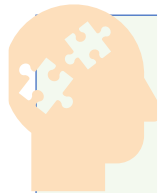
Help me to see my strengths and find ways to build on them.



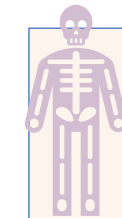
Help me to develop an identity beyond being someone who has a disability/uses a wheelchair.



Include me in discussions/planning about my life.



Teach me the skills to advocate for myself.

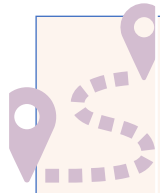


Help me to understand my body and my brain.



Find ways that I can join in, not reasons why I can't

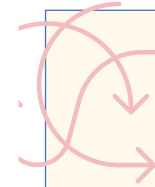
Parent Perspectives



Help to find a positive way forward.



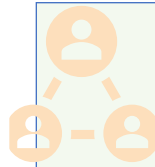
Encourage young people to take the lead in their health and therapy activities.



Work together with young people, their families and schools to advocate, problem-solve, and create opportunities.



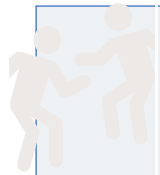
Build trusting relationships that support motivation and confidence.



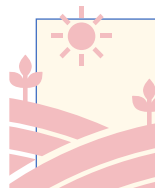
Connect families/YP with others who can share experiences, offer support, and inspire new possibilities.



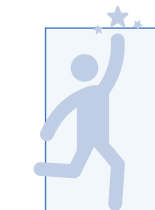
Provide families with the tools and confidence to navigate accessibility challenges.



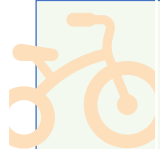
Support young people to see their potential.



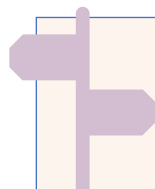
Offer practical ideas to include young people in everyday activities in ways that matter to them.



Set goals together that fit into daily life at home, school, and in the community.



Make therapy activities relevant, engaging, and connected to real-life experiences.



Ensure families have access to the right information at the right time.



Stay open to innovation and research that create more opportunities for participation.

Health Professional Perspectives



Support families to navigate the journey with confidence and realistic expectations



Empower young people and their families with knowledge about the condition



Work consistently across the care team to support families at every stage of the journey.



Meet the family where they are and shape care around their needs and goals.



Empower families with knowledge to support confident decision making



Advocate for access to services in all communities, including rural and remote.



Work with the whole team to make medical interventions meaningful in daily life



Build long term relationships based on trust, consistency and respect



Support flexible service delivery that responds to real family needs.



Plan ahead to reduce service gaps and support families consistently



Use early intervention to build confidence, identity and connections.



Map out clear pathways that support children and families with complex needs.



Acknowledge and support families navigating grief and change



Make evidence-based and condition informed decisions and recommendations.



Make therapy activities relevant, engaging, and connected to real-life experiences.



Offer practical ideas to include young people in everyday activities in ways that matter to them.



Champion young people and create opportunities to be active, connected and included in their communities.



Prepare young people for transitions in health care and beyond.



Share knowledge and collaborate across disciplines to grow and improve together



Understand and respond to barriers that make it hard for families to access care.

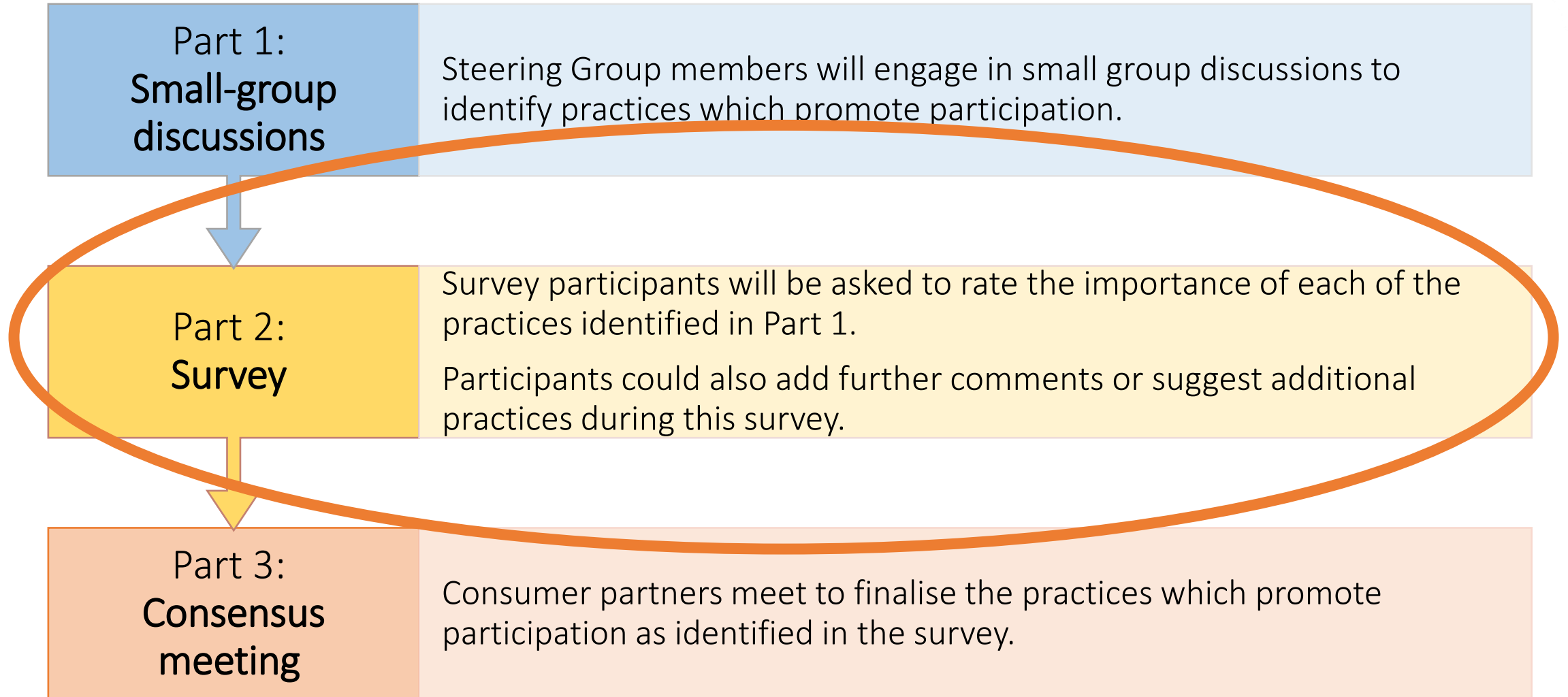


Create safe spaces for families to share openly and feel heard

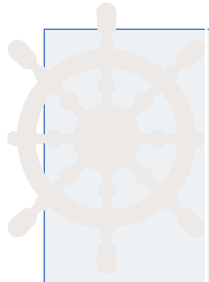


Meet families where they are and shape care around their needs and goals

Project Overview:



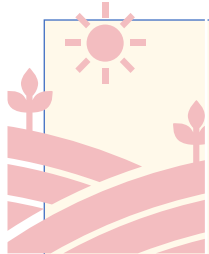
7 Key Practices



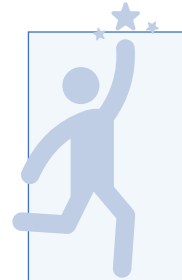
Prepare young people to be "self-managing adults"



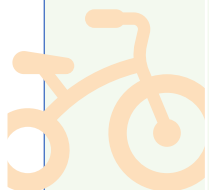
Walk alongside families and young people, and be flexible in meeting their needs.



Provide a clear picture of the future to help guide today's choices.



Provide the right support, in the right place, at the right time.

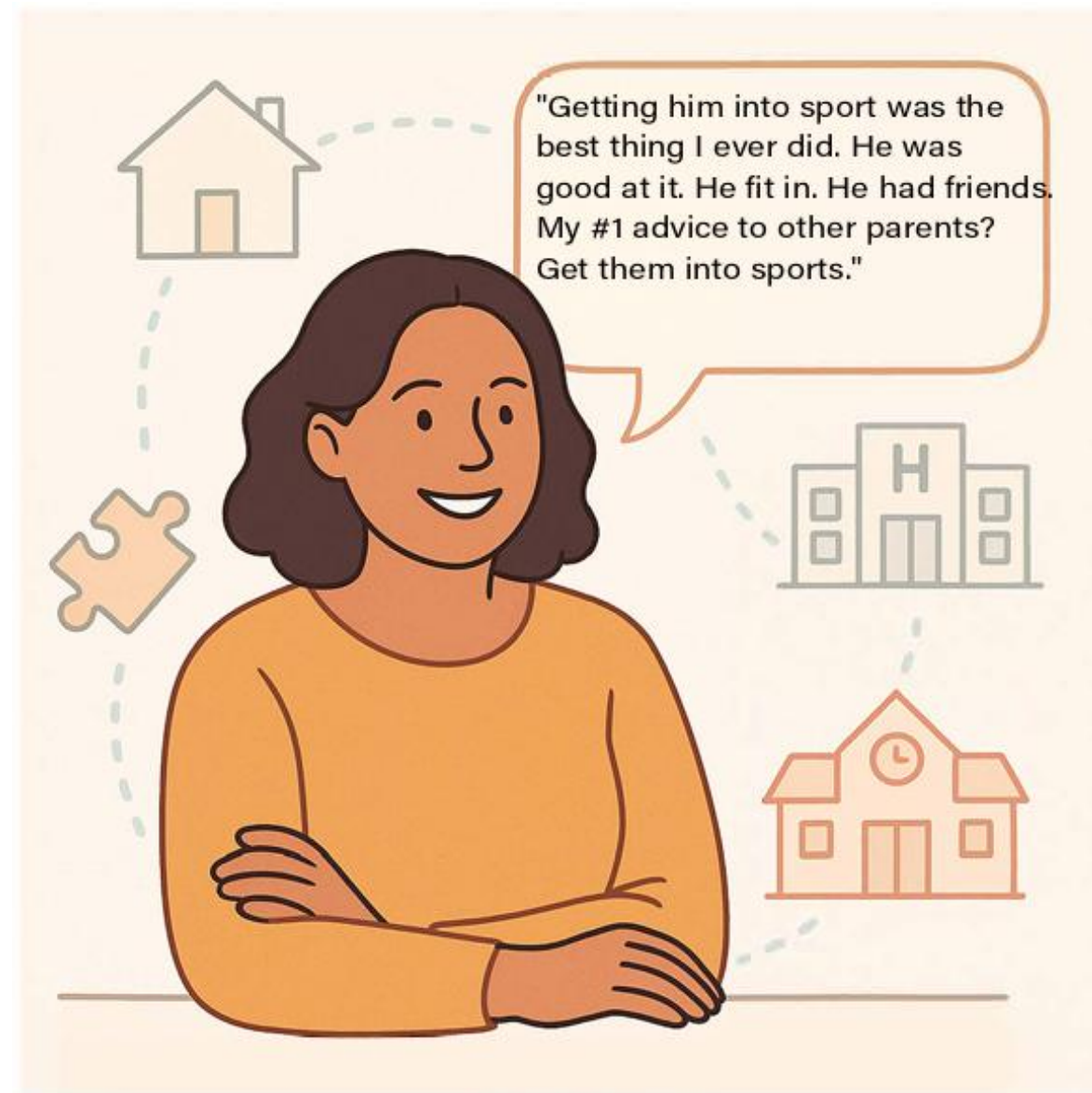


Help young people to develop their identity and connect with their communities

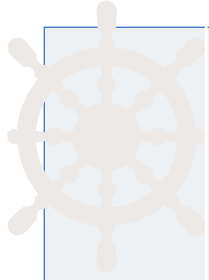


Be knowledgeable, innovative and open to exploring new ideas.





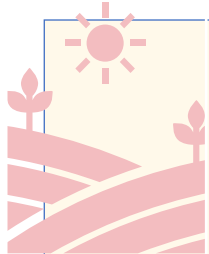
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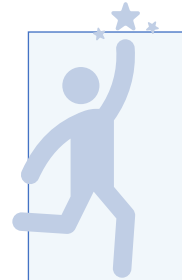
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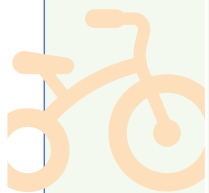
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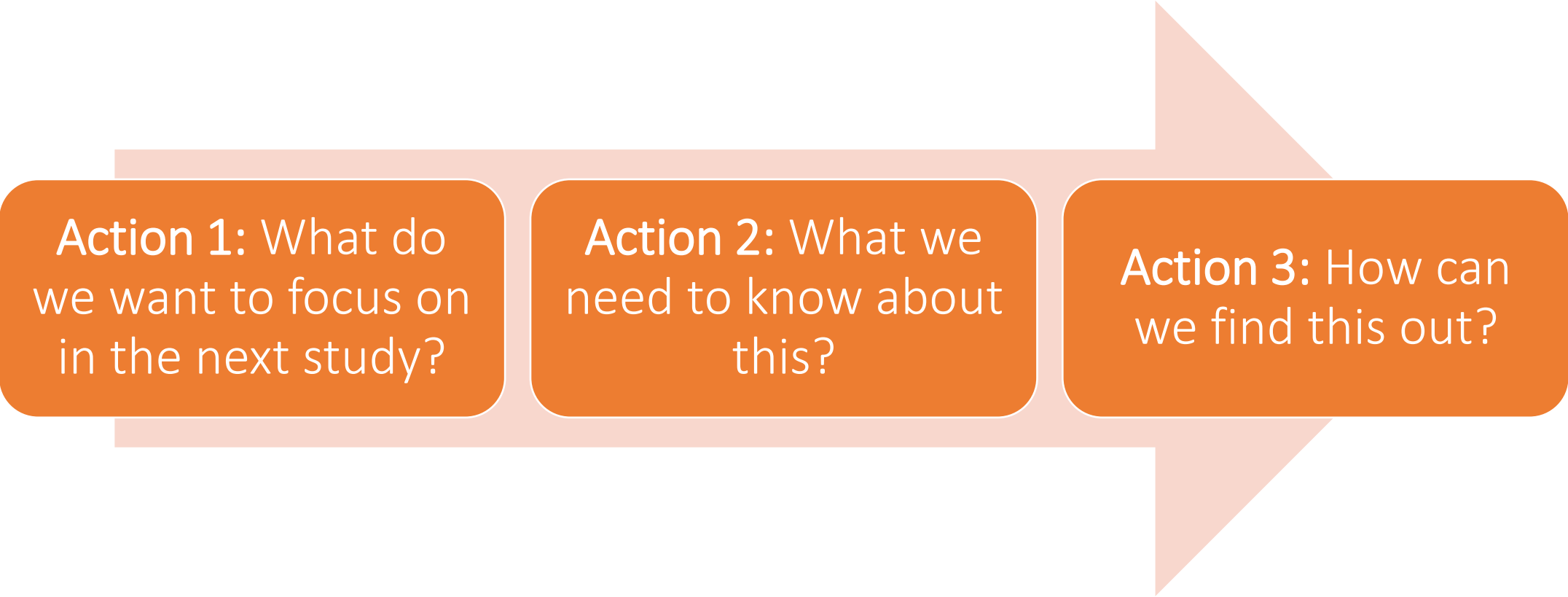
Help young people to develop their identity and connect with their communities



Be knowledgeable, innovative and open to exploring new ideas.

Where to next?

Our next steering group meeting will address 3 key questions:



Action 1: What do we want to focus on in the next study?

Action 2: What we need to know about this?

Action 3: How can we find this out?

Want to get involved?

Join our next steering group meeting:

Friday 14th November 1:30pm – 3:30pm

The meeting will be held both in-person at QCH and online via Zoom.

You can express your interest or reach out for information by emailing me:

j.thackeray@uq.edu.au



References

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