

# Siblings of individuals with neurodevelopmental disabilities: Exploring dynamic networks of risk and resilience to enable early identification, intervention, and sustainable scalable change.

Brittany Mann

Telethon Kids Institute

The University of Western Australia

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# Siblings of individuals with neurodevelopmental disabilities: A dynamic network exploration of risk and resilience factors impacting wellbeing

Brittany Mann & Emma Glasson

Telethon Kids Institute, The University of Western Australia

## BACKGROUND

Siblings of individuals with neurodevelopmental conditions may experience joys and struggles associated with the sibling experience.

Previous research finds both increased risk of psychosocial and behavioural difficulties in these siblings compared to controls, and also more opportunities for growth and resilience.

We need to understand more about the challenges and benefits of the sibling experience, and establish a shared language to understand siblings needs.

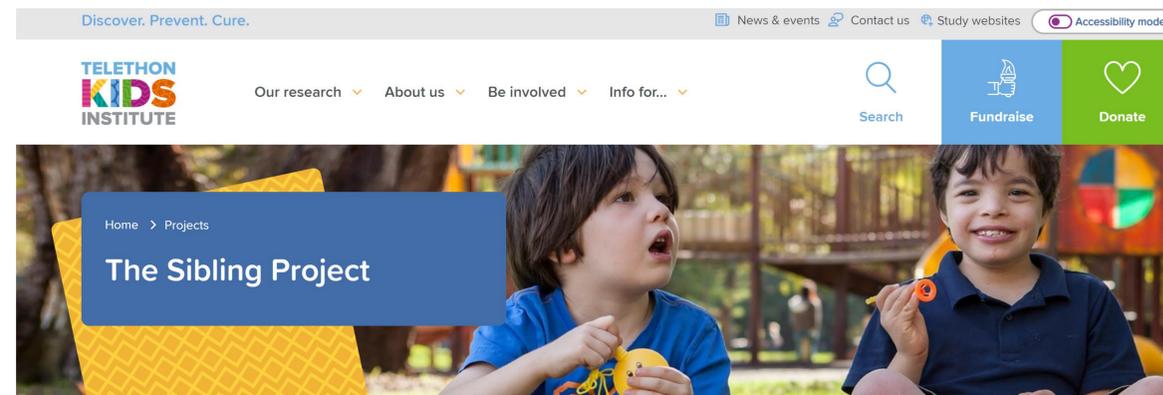
## RESEARCH QUESTIONS

- 1) What are the psychosocial, behavioural and neurocognitive characteristics associated with mental health and wellbeing of siblings of individuals with developmental disabilities as understood in the current literature, from a quantitative and qualitative perspective?
- 2) Which unique combinations of quantitative risk and resilience factors, identified using exploratory survey data, contribute to wellbeing outcomes in siblings of individuals with developmental disabilities, and how does this differ across sub-groups of siblings?
- 3) How do siblings describe and understand their own relationships and mental health, and which factors may be enhanced or reduced to improve their subjective experience of wellbeing?
- 4) Which neurocognitive and psychosocial variables are most central to risk and resilience networks, and which may be most modifiable with supports and interventions to improve wellbeing in siblings, evaluated from a quantitative (survey data) and qualitative (sibling subjective experience) perspective?

## CURRENTLY RECRUITING!

Three groups are eligible to participate, aged over 8: a) siblings of children with any disability (mental health or physical) or developmental disorders, b) siblings of children without any disability, and c) only children without any siblings. All participants will be entered into a monthly prize draw!

Are you a sibling OR an only child aged over 8?  
[http://uwa.qualtrics.com/jfe/form/SV\\_7QCTxVDsmO5Dc5T](http://uwa.qualtrics.com/jfe/form/SV_7QCTxVDsmO5Dc5T)  
or scan this QR code →



## SURVEY METHODS

We used an integrated knowledge translation approach to partner with siblings. We established a Sibling Advisory Panel of siblings who have a brother or sister with a disability, aged 5 (Parent-Buddy advisors) to 45. We believe in participatory, inclusive research methods. An exploratory mixed methods design has been used to date in co-designing, piloting and launching the Sibling Project Survey, and designing the Visual Voices information booklet

These siblings will continue to partner with us throughout all study stages, and we are recruiting more this year! Sign up here:  
<https://telethonkids.org.au/siblings>

## REFERENCES

Macks, R. J., & Reeve, R. E. (2007). The Adjustment of Non-Disabled Siblings of Children with Autism. *Journal of Autism and Developmental Disorders*, 37(6), 1060-1067. doi:10.1007/s10803-006-0249-0

Mandlco, B., & Webb, A. E. M. (2015). Sibling perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review: Sibling Perceptions of Living With a Young Person With Down Syndrome or Autism Spectrum Disorder. *Journal for Specialists in Pediatric Nursing*, 20(3), 138-156. doi:10.1111/jspn.12117

Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors that May Affect the Health of Siblings of Children Who Have an Intellectual/Developmental Disability - review. *Journal of Policy and Practice in Intellectual Disabilities*, 16(4), 273-286. doi:10.1111/jppi.12309

## DATA COLLECTION AND ANALYSIS

Data collection and analysis techniques vary across the Phases: 1) systematic reviews, 2) mixed methods survey, designed to be exploratory and data-driven. It includes validated and age-normed instruments which measure the constructs listed in the Siblings Resiliency Framework., 3) Visual Voices qualitative study, 4) quantitative follow-up survey, 4) co-produced forum.

Quantitative analysis: understand dynamic relationships between domains of risk and resilience; graph theory analysis allows relationships within a network to be qualitatively explored. The new method used in this thesis will test a Bayesian network estimated in an exploratory environment to generate hypotheses, and replicate these networks in a confirmatory setting.

Qualitative analysis: grounded theory will be applied for textual analysis. Open-ended questions will be analysed using thematic content analysis and coding procedures with NVivo 11 software.

Follow the team for updates!

Twitter

<https://twitter.com/neurobrittany>  
[https://twitter.com/emma\\_glasson](https://twitter.com/emma_glasson)  
<https://twitter.com/telethonkids>

## SIGNIFICANCE

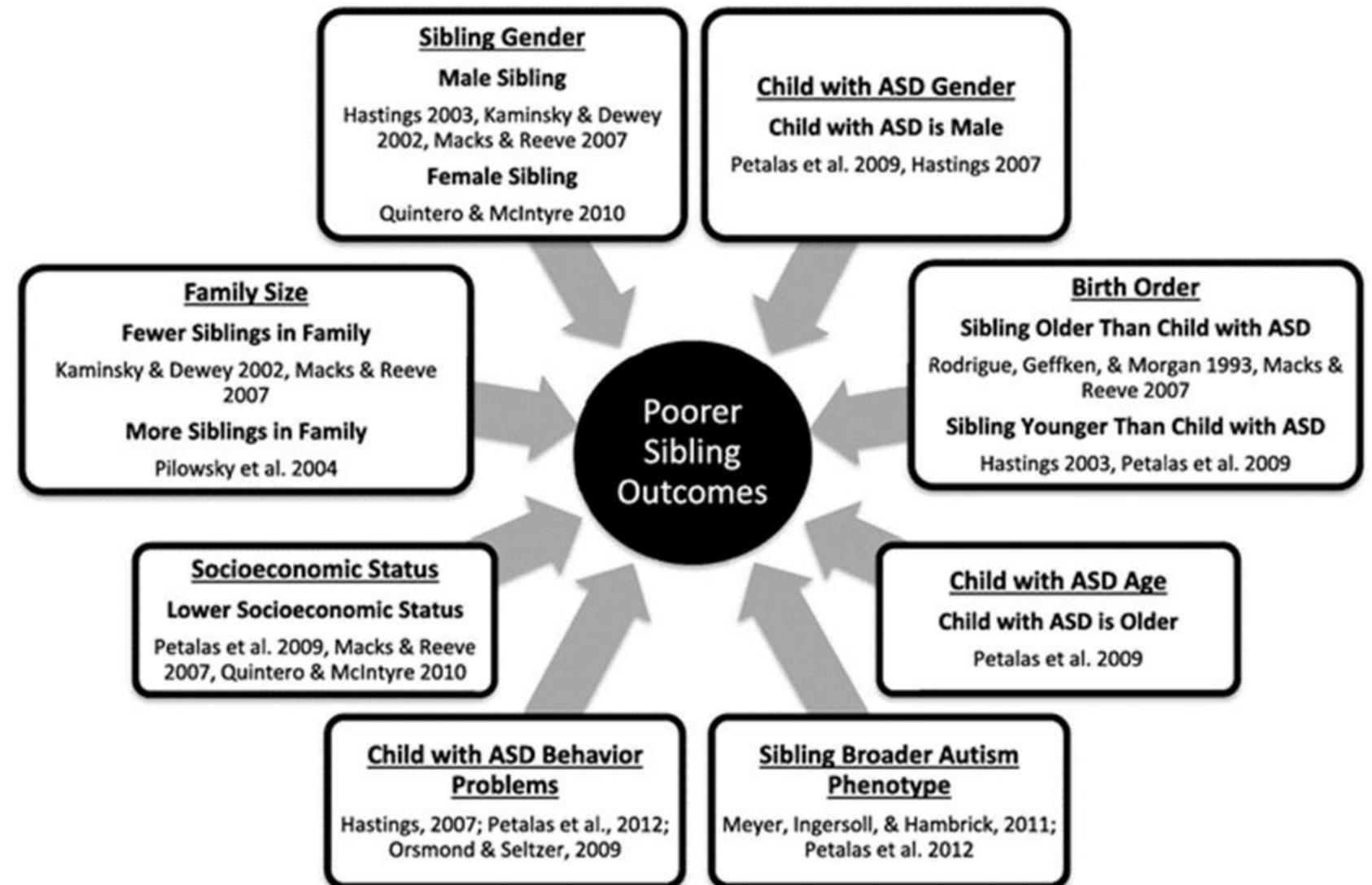
Data collected will be used to extend our understanding of risk and resilience factors influencing sibling wellbeing outcomes, and identify determinants of wellbeing, including modifiable risk and resilience factors which can be targeted for early identification and implementation of sustainable change through supports and services.

# Deficit based models

Focus is always on the 'bad'

What about the 'good'?

Risk and resilience are not flip sides of the same coin.



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# Learning from siblings

The cognitive perspective (What is the sibling's understanding of the disorder? What are the sibling's cognitive strengths and weaknesses?)

The emotional perspective (How do individual family members manage their feelings? What is the sibling's current experience?)

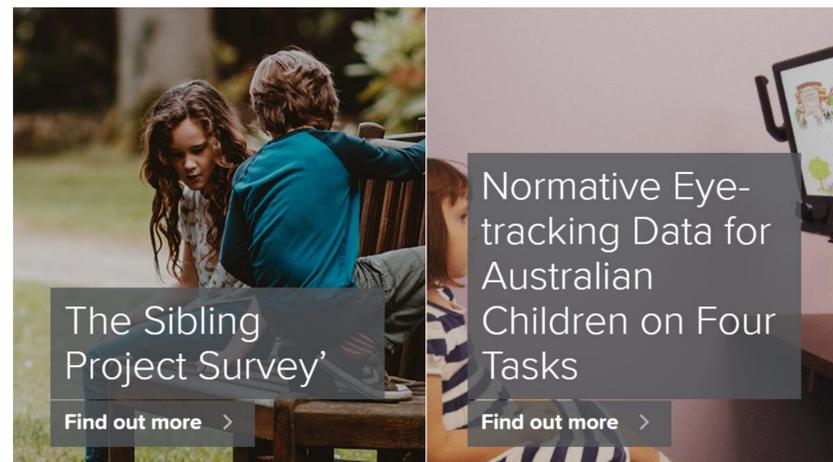
The perspective of effective family action (How do families discuss and solve problems and how do they manage stress?)

The chronological perspective (What is the sibling's understanding of the disorder across time? How does the sibling experience change? How do siblings develop as individuals?)

Problem solving strategies are key in shifting the balance from vulnerability to resilience.

The sibling experience may vary over time depending on the developmental progress of the affected child and on the understanding of the unaffected sibling.

The sibling individual characteristics may vary at baseline and change over time. Causality is difficult to infer for any psychosocial, emotional, behavioural, or cognitive outcomes.



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# Is there a gap?

Here's what we don't know:

What combination of factors, and at which age, may confer the greatest risk for poorer outcomes amongst these siblings, and what are the best intervention and support approaches to assist their development?

How can we identify the risk/resilience factors with the greatest impact and malleability to target with personalised interventions in subgroups of siblings with differential responses to adversities?

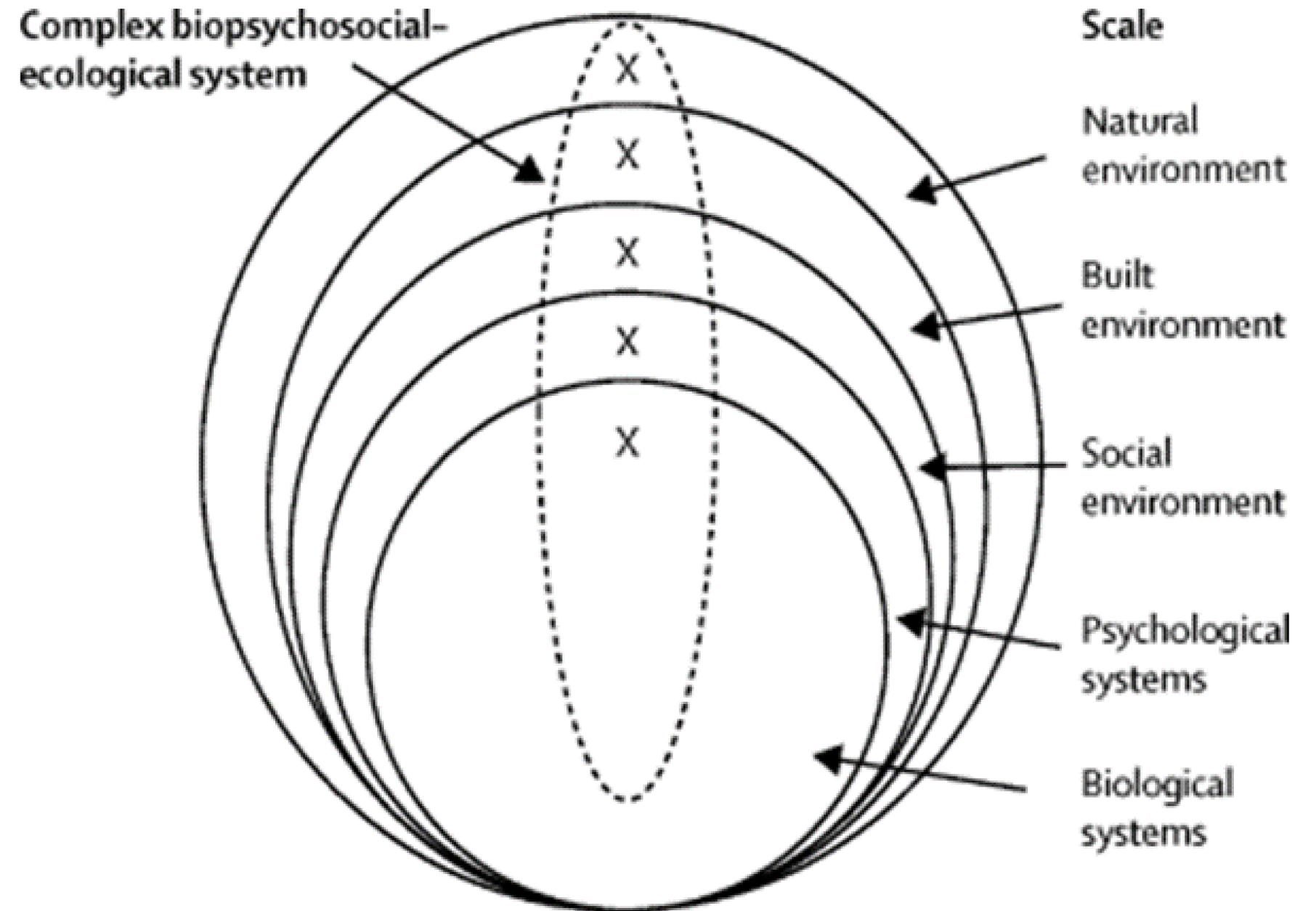


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# Bronfenbrenner's ecological theory

The elements are grouped into a whole system made of multiple scales or subsystems that are co-dependent for their functioning if resilience is to occur.

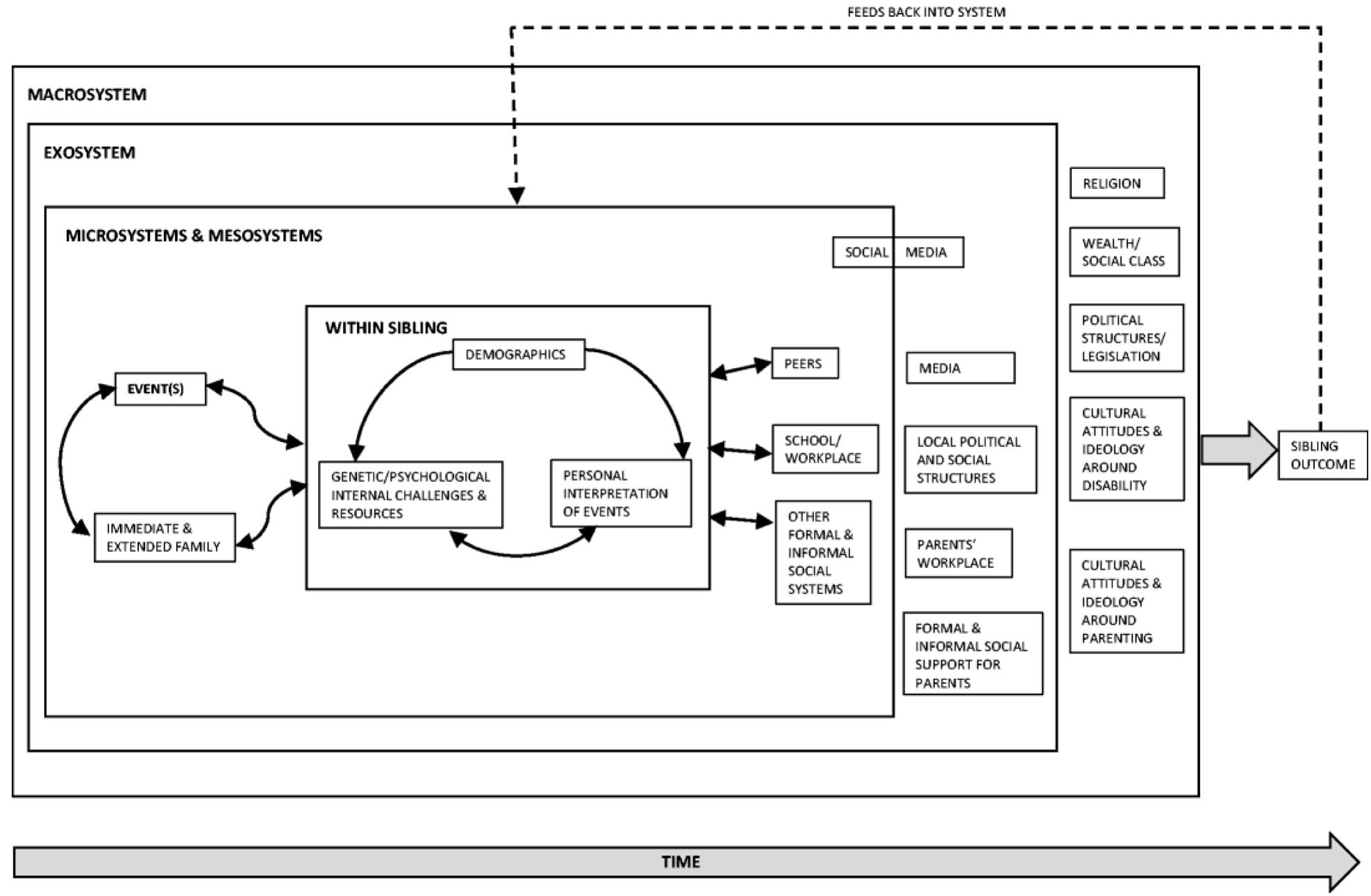
Image from: Ungar, M., & Theron, L. (2020). Resilience and mental health: How multisystemic processes contribute to positive outcomes. *The Lancet Psychiatry*, 7(5), 441-448. doi:10.1016/s2215-0366(19)30434-1



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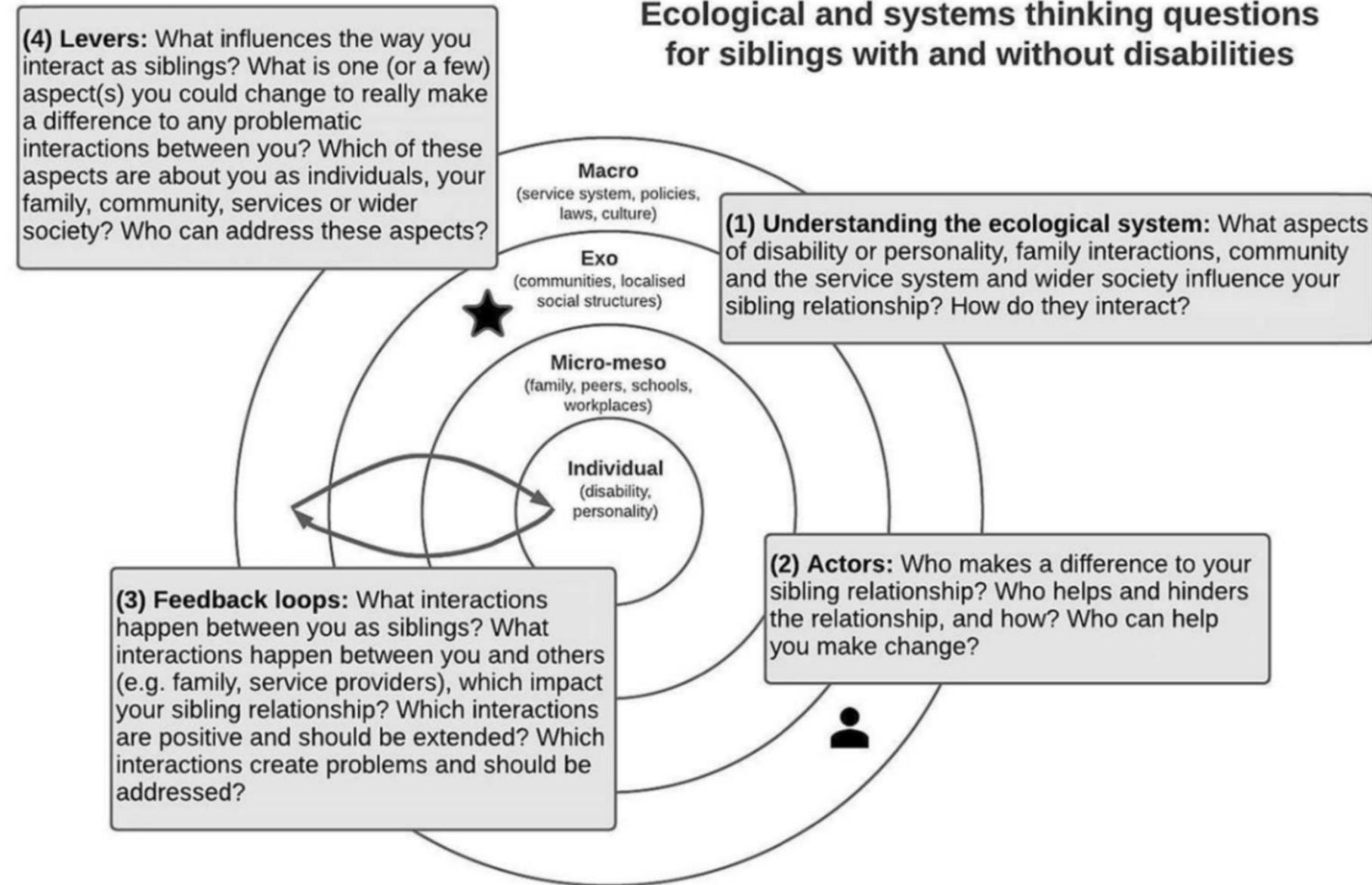
# Siblings Embedded Systems Framework

Kovshoff, H., Cebula, K., Tsai, HW.J. *et al.* Siblings of Children with Autism: the Siblings Embedded Systems Framework. *Curr Dev Disord Rep* 4, 37–45 (2017). doi:10.1007/s40474-017-0110-5



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## Ecological and systems thinking questions for siblings with and without disabilities



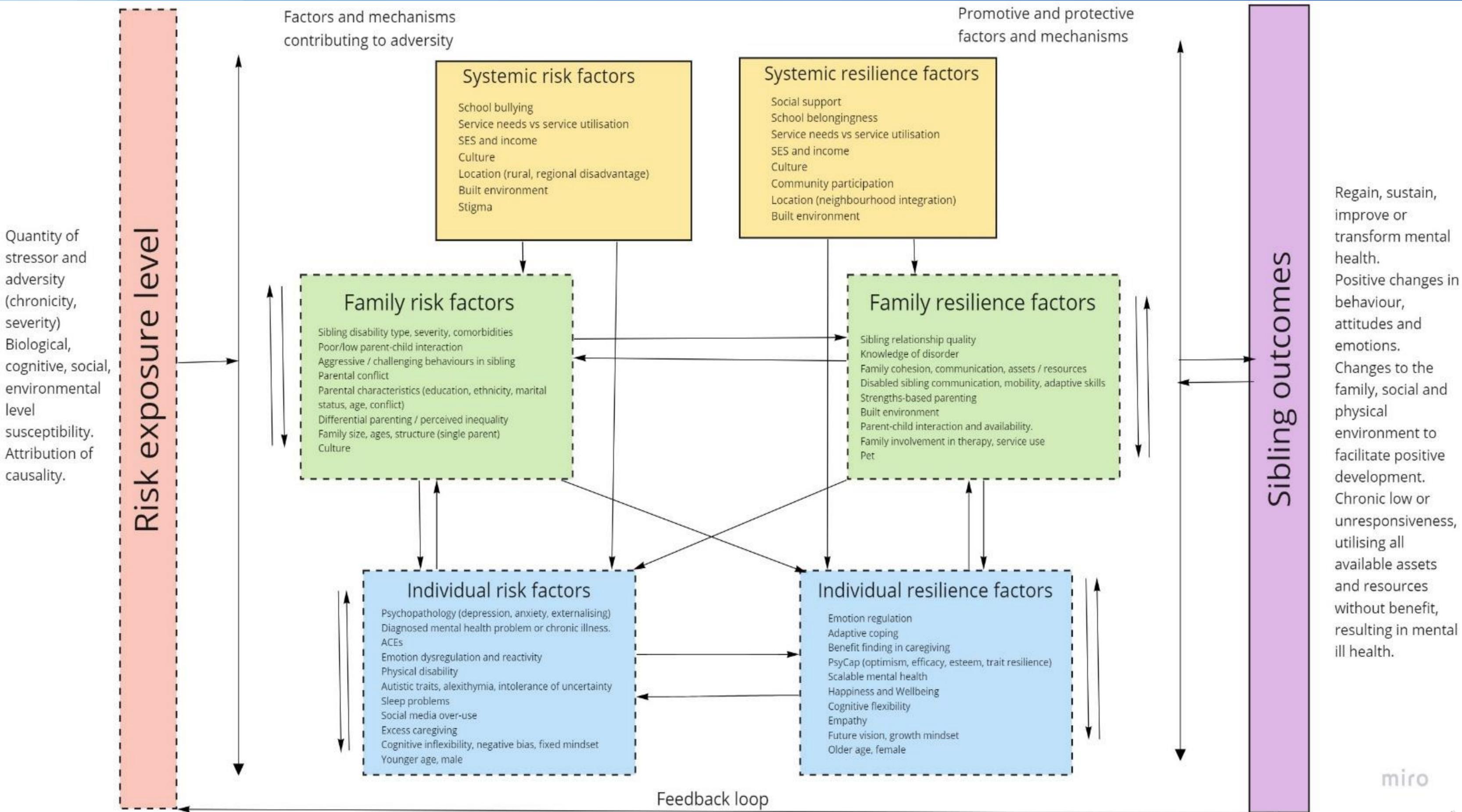
## A Practice Tool?

Meltzer, A., Muir, K. An ecological and systems thinking approach for support to siblings with and without disabilities. Soc Theory Health (2021). <https://doi.org/10.1057/s41285-020-00158-6>

**Fig. 3** Practice tool for sibling support practitioners in health and social care to use with siblings (to be read clock-wise)



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# Phase 1: Review, identification, consultation

Methods: Published on PROSPERO.

Research output

- SR1: Mental health and wellbeing in siblings of individuals with developmental disorders: a systematic review and meta-analysis of quantitative studies.
- SR2: The experience of quality of life, strengths and difficulties of siblings of individuals with developmental disorders: a meta-synthesis of qualitative studies.
- R3: A realist evaluation of the effectiveness of interventions and support groups for siblings of individuals with disabilities: contextual factors and mechanisms associated with improvements on primary outcome measures.



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# Phase 1: Interim Results

**Quantitative: 46 studies**  
(wellbeing or mental health = SDQ, CBCL)

**Qualitative: 23 studies** (quality of life or relationship focus)

**Population based: 16 studies** (systems-levels)

**Interventions: 22 studies** (sibling groups or parent-child interactions)

Focus is on non-modifiable factors; individual-level risk or resilience factors are neglected; focus on the 'impact' (deficit language) of the disabled sibling; most studies are parent-report; most are ages 14-18 or later adulthood.



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# Phase 2: The Sibling Project Survey



Welcome to the Sibling Project Survey!



THE UNIVERSITY OF  
**WESTERN  
AUSTRALIA**



Creation of our Sibling Advisory Panel and a participatory, inclusive research framework.

Design and release the Sibling Project Online Survey.

Examine individual, family and systems-level risk and resilience factors, profiles most likely to result in optimal sibling wellbeing, and predictors and modifiers of these.

Describe and examine psychosocial outcomes and cognitive-behavioural patterns in sibling groups.

Explore, compare, and analyse qualitative self-reported sibling relationship experiences, perspectives on risk and resiliency, and hopes for their future and that of their siblings.

Special interest groups: siblings of children with FASD, autism, and 'only children'. **We need you!**

Methods: Quantitative Bayesian network analysis, qualitative thematic analysis.

**Participate today!**

[http://uwa.qualtrics.com/jfe/form/SV\\_7QCTxVDsmO5Dc5T](http://uwa.qualtrics.com/jfe/form/SV_7QCTxVDsmO5Dc5T)

or scan this QR code →



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# Survey parameters

← Sneak peak mobile version!

Now recruiting!

Scan this QR code!



Demographics: sibling characteristics (age, sex, ethnicity, mental and physical health problems or diagnoses); disabled-sibling characteristics (age, sex, disability type and severity, date of diagnosis, other mental or physical health problems); parent characteristics.

Psychological capital: Efficacy (New General Self Efficacy Scale), Resilience (CD-RISC 10), Optimism Scale, Emotion Regulation (ERQ-10)

School/university: study status, absenteeism, Student Subjective Wellbeing Questionnaire.

Bullying

Service use

Sibling Relationship (Sibling Relationship Inventory, Sibling Need and Involvement Profile).

Parent-child relationship (various communication and strength of relationship scales)

Social support (MSPSS)

Knowledge of disorder (custom questions)

Caregiving (The Perceived Impact of Child Care-giving Scale)

Empathy (Adolescent Measure of Empathy and Sympathy)

Psychopathology: Depression (PHQ-9), Anxiety (GAD-7), Youth Externalizing Behavior Screener, self-harm, autistic traits (AQ-10 self-report adolescent), Perth Emotion Reactivity Scale, Perth Alexithymia Scale, Intolerance of Uncertainty (IU-12), Cognitive Flexibility (BRIEF-SR)

Happiness (Happiness Ladder)

Wellbeing (SWLS)

Coping (KidCope)

COVID Specific anxiety and health questions

3 open-ended questions about their strengths, qualities, experiences and relationships.



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Fig. 8

Everything is sort of scary...



This tree is beautiful, and you can see where it is going, until it goes in the dirt. And then you have no idea where it goes after that. And I kind of felt, that's how my mind works. I like my thoughts, I like the way I think, I like the way I do things, but when I have anxiety, that's when the roots become that sort of tangled mess and everything is sort of scary, and I don't know where things are going, but I just have to remember at the end of the day, it still all leads back to the tree, it all leads back to me. I am not my anxiety. It is just something that happens. I looked at that tree, and I felt like things are going to be okay, no matter how bad things get, I am still me, and that is not going to change.

Marshall C.

*I am not my anxiety.*

# Phase 3: Visual Voices

*Photos, drawings and narratives capturing the sibling-disability experience, their quality of life, and risk and resilience indicators.*

With siblings as co-designers, create and implement a method of showcasing artwork and narratives online, and develop an Executive Report of findings from the qualitative synthesis.

Methods: 1) recruit participants, 2) provide an information booklet online and weekly prompts with Qualtrics links to upload creative pieces (eg. photos, drawings, short stories), 3) analyse creative pieces, 6) share sibling-nominated pieces online via a Sibling Showcase, 7) disseminate findings across communities and with policy-makers.

Recruiting now! <https://telethonkids.org.au/siblings>

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# Phase 4: Continuity and Change

*Purpose: Design and implement the longitudinal component of the Phase 2 survey to investigate chronogeneity of sibling experiences and outcomes.*

Investigate risk and resilience factors and other predictors of wellbeing outcomes among siblings across two time points.

With input from the Sibling Advisory Panel and using results from T1 Survey and Visual Voices, identify key risk and resilience factors which may interact and change over a 12-18 month period to include in the T2 Survey.

Possible sub-survey for 'high risk' groups (autism, FASD)

Other items/instruments may be removed or added, on advice from our Sibling Advisory Panel and based on T1 data analysis.



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# Phase 5: Sibling Summit



Purpose: Design and implement the Sibling Summit, an opportunity for siblings to connect, innovate, and uplift; to become co-researchers in analysing previous Phases; and co-designers of a multi-arm intervention and support program, to facilitate, enhance and optimize resilience factors in siblings and families.

The Summit will include three sessions designed by the Sibling Advisory Panel, and a Resilience Room Series. This has the goal of encouraging siblings to apply skills learnt throughout the Summit, such as cooperation, problem solving, social and emotional regulation, self-compassion and mindfulness.

The Sibling Advisory Panel (with new recruits accumulated over the next years), and results from the previous Phases, will be integral to determining the direction and design of the Sibling Summit and the plan to co-create the RCT and digital platform.



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# Contribution

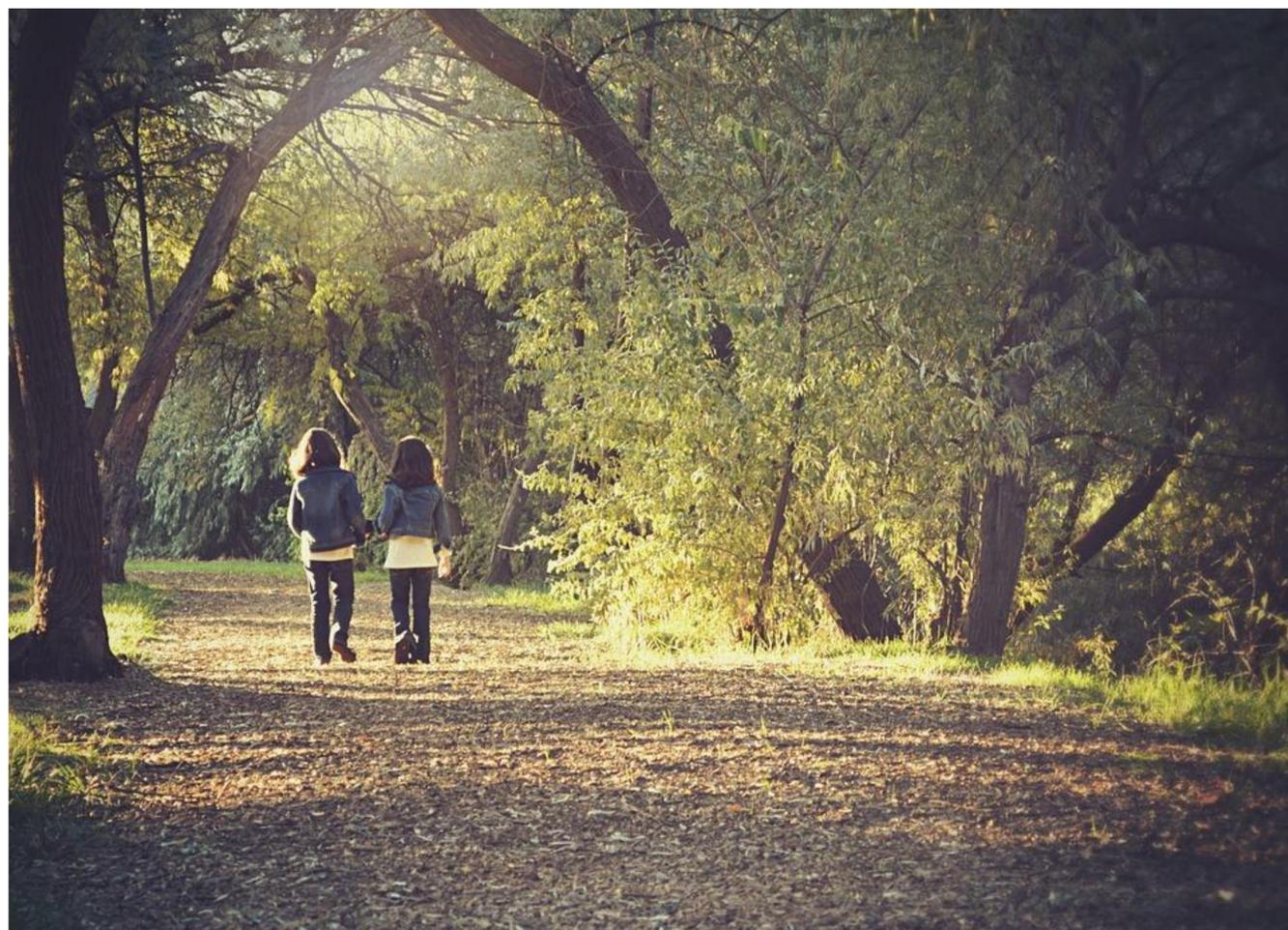
Here's what we will have accomplished:

- Presenting siblings as independent agents with outcomes not necessarily conditional upon the presence of a disabled sibling.
- In keeping with the realist model, siblings and stakeholders are included as co-designers throughout the research lifespan.
- Exploring sibling characteristics and experiences with a dynamic life-course approach.
- Applying Bayesian network analysis for the first time within a sibling framework to conceptualise risk and resilience factors as a complex interrelated system.
- Designing and implementing qualitative research including photography, drawing, and narrative writing, to complement quantitative data collection.
- Co-design of a novel Sibling Summit and multi-arm RCT for scalable mental health targeting empirically-supported resilience factors.



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The Sibling Project... join us today!



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