



# PROJECT SUMMARIES

JULY 2019



# INTRODUCTION

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The Kids in Action network is being established to increase the profile of participatory research with children, to offer local projects increased credibility in their efforts to fund and resource their projects, to provide a platform for shared learning and development of these methods, and a means for generating resources to share with others to support the use of participatory health research with children. There is also scope for the Kids in Action network to be a platform for providing child input into debate about global issues.

It has been established under the auspices of the International Collaboration for Participatory Health Research ([www.icphr.org](http://www.icphr.org)) and is being coordinated by Professor Lisa Gibbs, Director of the Jack Brockhoff Child Health and Wellbeing Program and Co-Chair of the Children's Lives Initiative at the University of Melbourne.

The Kids in Action network was launched end September 2016 and currently has membership on 5 continents.

For further information contact Lisa Gibbs: [lgibbs@unimelb.edu.au](mailto:lgibbs@unimelb.edu.au) or go to <http://www.icphr.org/kids-in-action.html>



# CURRENT MEMBERS

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- **Professor Tineke Abma**, VU University Amsterdam
- **Professor Lala Acharya**, Purdue University
- **Camillia Acosta**, University of Melbourne
- **Emilie Achermann**, PH Zurich University
- **Ulysses Archie**, Baltimore Gift Economy, Baltimore, USA
- **Professor Hayda Alves**, Federal Fluminense University, Brazil
- **Manou Anselma**, Amsertdam University Medical Centre, Amsterdam, The Netherlands
- **Therese Bauer**, PH Zurich
- **Tanya Benjamin**, Western University, Canada
- **Professor Jacqueline Bhabha**, FXB Center for Health and Human Rights, Harvard
- **Dr Ali Black**, University of the Sunshine Coast
- **Dr Karen Block**, University of Melbourne
- **Femke Boelsma**, VU University Amsterdam
- **Dr Tobias Buchner**, Queraum Cultural and Social Research
- **Professor Irma Brito**, Nursing School of Coimbra, Portuga
- **Professor Rona Campbell**, University of Bristol, Bristol, UK
- **Dr Jennifer Cartmel**, Griffith University
- **Marilyn Casley**, Giffith University
- **Meg Chin**, University of Melbourne
- **Dr Ann Dadich**, Western Sydney University
- **Professor Lynn Davies**, University of Birmingham
- **Assistant Professor Christine Dedding**, VU University Amsterdam
- **Sharon Eggins**, Hippy Australia
- **Dr Ani Etokidem**, University of Calabar
- **Jennifer Fane**, Flinders University
- **Alexa Ferdinands**, PhD Candidate, University of Alberta, Edmonton, Canada
- **Dr Anita Franklin**, Coventry University
- **Dr Jana Fried**, Coventry University
- **Dr Kwabena Frimsong-Manso**, University of Ghana
- **Professor Lisa Gibbs**, University of Melbourne
- **Assistant Professor Brenda Gladstone**, University of Toronto
- **Dr Rebekah Grace**, Macquarie University, New South Wales
- **Gia Grier**, Morgan State University, Baltimore, USA
- **Geraldine Harris**, Griffith University, Queensland
- **Dr Jeni Harden**, University of Edinburgh
- **Roger Holdsworth**, University of Melbourne
- **Dr Colette Kelly**, National University of Ireland, Galway, Ireland
- **Krystyna Kongats**, University of Alberta
- **Revathi Krishna**, Monash University
- **Eva Lems**, VU University Amsterdam
- **Dr Maria Magnusson**, University of Gothenburg and Angered Hospital
- **Robyn Mansfield**, Yarra Ranges Council, Victoria
- **Katitza Marinkovic**, University of Melbourne
- **Dr Magda Matache**, FXB Center for Health and Human Rights, Harvard
- **Nikias Obitz**, PhD Candidate, Technische Universität Dortmund, Germany
- **Dr Siobhan O'Higgins**, National University of Ireland, Galway
- **Dr Meredith Overman**, Maastricht University, Maastricht, The Netherlands
- **Dr Margareta Rämgård**, Malmo University
- **Associate Professor Gerry Redmond**, Flinders University
- **Dr Harry Shier**, Queens University Belfast
- **Kerry Smith**, Griffith University, Queensland
- **Dr Suja Somanadhan**, University College Dublin
- **Professor Kay Tisdall**, University of Edinburgh
- **Professor Cheryl Vardon**, Queensland Family and Child Commission
- **Andrea Vasquez**, CIGIDEN
- **Professor Fernando Wagner**, University of Maryland



We are researchers. We are responsive adults who value children and childhood. And we are beginning a dialogue.

We value research *with* **CHILDREN**  
& we want to engage *with*  
as **co-researchers** and **collaborators**.

Authentic relationships matter to us.

And we are focused on values and ethics.

**WE CARE ABOUT CHILDREN'S RIGHTS.**

So, we want our work with children to communicate  
**a sense of mutual respect.**

We believe in children's capabilities, competencies,  
agency and potentials.

*We seek to listen with children, and to see with children.*

**And the more we listen, and the more we see, the more we realise how important it is to listen — really listen — to children and their perspectives. To see the world through their eyes.**

**And to understand and support what matters to them.**

*We want our engagement with children to generate learning  
– for children, for us, for communities, & for decision-makers.*

*We want to enable spaces for shared learning  
about participatory research with children  
and to create resources that we can share.*

**We believe in unity, equality, love and hope.**

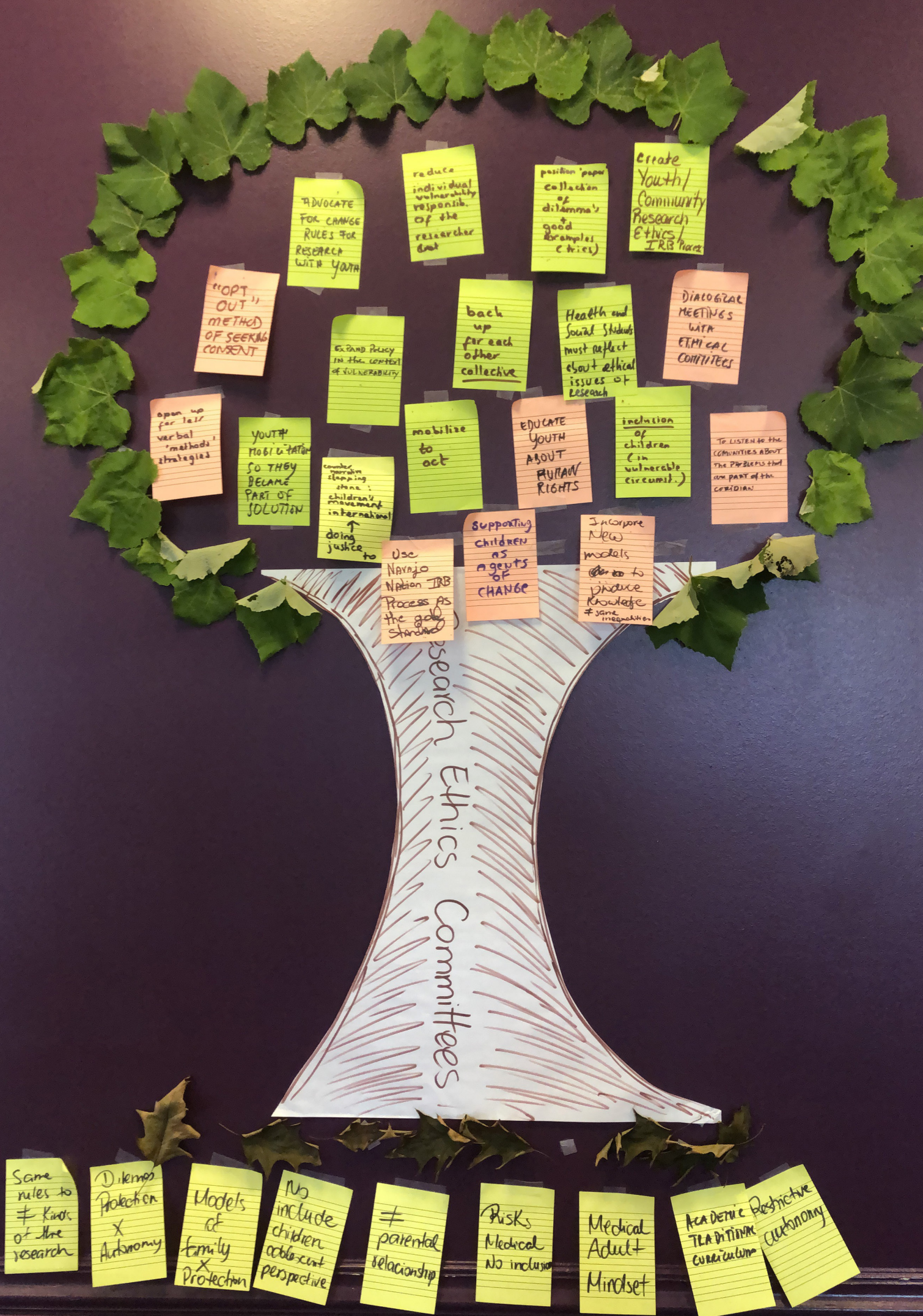
**A pedagogy of hope. A pedagogy of listening.**

**A pedagogy of relationship.**

These are what guide us.









# SUMMARY

So far, the members of the Kids in Action Network have or are collaborating in the following initiatives:

5

Collaborations for building a vision together (internal surveys, booklets, online repository, 2 manifestos)

4

ICPHR Annual Working Meetings

3

Articles in progress (still being written)

2

Collaborative research projects

1

Conference presentation

1

Collaborative event

2

Book chapters



## Photographs

Participatory research: how ethics committees in different nations include the voices of children and adolescents toward democratic knowledge. Activity led by Dr Hayda Alves during ICPHR Annual Working Meeting, Baltimore, June 2019.

# CURRENT PROJECTS

**Project Name**

Children's Views about the Family Place

**Project Coordinator**

Jennifer Cartmel

**Project Location**

Logan, Australia

**Age Group Involved in Research Decisions**

Children (5 years and under)

**Project Description**

The Family Place is a unique place-based program in Logan that is currently engaging with families through a soft-entry, universal approach to early intervention and prevention. The Family Place is a strengths-based practice where staff and collaborative partners work together to provide multi-level support to families and the community. Families create their own family support programs through purposeful relationships and interactions (TSA CfC L, 2015). The centre is building parental capacity, parents are connecting with other services and families are experiencing a sense of belonging in the community. This is evident from the feedback given by parents in the 2014 evaluations (TSA CfC L, The Griffith Knowledge Partnership & C&K. (n.d.). This project is an opportunity to see feedback from the children who attend.

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**Project Name**

Young Edinburgh Action

**Project Coordinator**

Kay Tisdall

**Project Location**

Edinburgh, United Kingdom

**Age Group Involved in Research Decisions**

Children (10-14 years)

Youth (15-25 years)

**Project Description**

Young Edinburgh Action (YEA), is an innovative approach to implementing City of Edinburgh Council's Young People's Participation Strategy and is informed by the views of young people and professionals, academic theory and the needs of the council.

YEA has developed a partnership with the Centre for Research on Families and Relationships to capture the unique qualities of the practice and share learning about the approach.

YEA addresses issues across children's services, from health to social work to planning.



**Project Name**

When a Child Dies from a Life-Threatening Condition: Hearing the Voices of Bereaved Siblings

**Project Coordinator**

Meg Chin

**Project Location**

Melbourne, Australia

**Age Group Involved in Research Decisions**

Children (6-9years)

Children (10-14years)

Researchers

**Project Description**

The perspectives of children regarding their lived experience of having a brother or sister die from a life-threatening condition is an unexplored area in published research. The death of a sibling in childhood has a substantial life-long impact for a child, yet there is a distinct lack of voice from the children who have experienced such a significant loss. Many questions arise in determining how bereaved siblings can be best supported in bereavement and experience post-traumatic growth. Exploring this sensitive area to develop greater knowledge and insight is best achieved by actively involving and engaging children, who have experienced the death of a sibling, in participatory research.

**Aim:** The aim of this PhD research is to develop greater knowledge and insight from bereaved children about their experiences, understanding and support needs after the death of a sibling from a life-threatening condition.

**Objectives:**

- To explore, consider and illuminate the issues, feelings and lived experiences of bereaved siblings.
- To provide opportunity for bereaved siblings be supported, active research participants.
- To use knowledge gained from bereaved siblings to inform and enhance service delivery and assist in promoting post traumatic growth outcomes for bereaved siblings.
- To use knowledge gained from bereaved siblings to inform practice and policy issues.

**Design:** Practice-based participatory research with children. Setting: Non-profit community-based paediatric palliative care organisation in Melbourne Australia.

**Participants:** Children in middle childhood (8-12years) who have had a sibling die from a life-threatening condition.

**The key questions to be explored/examined are:**

1. What do bereaved siblings say about their bereavement experience?
2. What challenges do bereaved siblings face in peer relationships?
3. How do bereaved siblings want to be supported?
4. What are the implications for bereaved children of actively participating in research?

# CURRENT PROJECTS CONT.

**Project Name**

VIPER - Voice, Inclusion, Participation, Empowerment, Research

**Project Coordinator**

Anita Franklin

**Project Location**

England

**Age Group Involved in Research Decisions**

Children (10-14 years)

Youth (15-25 years)

**Project Description**

VIPER (voice, inclusion, participation, empowerment and research) was a three-year project funded by the UK Big Lottery Fund to research young disabled people's participation in decisions about services. The project was delivered by a consortium that included the Council for Disabled Children, National Children's Bureau, The Children's Society and the Alliance for Inclusive Education and a team of disabled young researchers (the VIPERS) recruited specifically to the project. We set out to research disabled children and young people's participation in decision-making about local services with the aim to improve services used by disabled children and young people in England.

The ethos of this project started with the principle that all young disabled people have the same rights as young non-disabled people to participate in decisions and issues that affect them. A rights based approach challenges the view that young disabled people need extra care and protection that would be considered unacceptable for non-disabled young people. This view disempowers young disabled people and limits their right to choice and control in their lives.

A key principle for this research and the partnership was the social model of disability and all project activities adopted this approach. A social model of disability approach places the responsibility of removing the barriers with society and NOT with the young disabled person. This has meant that the research focused on identifying and removing the attitudinal, physical, economic and social barriers that prevent young disabled people from participating in decision making. These barriers are created by negative attitudes in society towards people with impairments or differences.

The project involved a large research programme. We reviewed existing research, carried out a consultation exercise with organisations working with disabled children and young people to look at current practices, and undertook in depth case studies using focus-groups and interviews with disabled young people and professionals to explore how disabled young people can successfully and meaningfully participate in decision-making about services, organisations and policies. All of the Viper researchers were given opportunities to take part in all aspects of the research and a choice about how much or how little they got involved in each stage of the project. For a small minority, attending the meetings was all that they wanted to do. But for most, they chose to do much more and we tailored opportunities to their individual interests. All Vipers stayed involved in the project from beginning to end, a period of three years commitment.



**Project Name**

Using photovoice to explore the experience of young carers

**Project Coordinator**

Krystyna Kongats

**Project Location**

Toronto, Canada

**Age Group Involved in Research Decisions**

Children (10-14 years)

**Project Description**

Young carers are typically between the ages of 5-18 years of age who provide care for a family member such as a parent, sibling or grandparents who may be experience a chronic or life-limiting illness, disability, addiction or mental illness. Young carers are a relatively hidden yet large population in Canada; it is estimated that 12% of young people are young carers. Young carers provide practical, personal and emotional support that can have positive benefits on the young carer, however these responsibilities can also have negative impacts on young people's health, safety and development. This burden is not about the amount of responsibility and care young carers provide, but it is about how they are affected by it. [Organization name] is one of the few organizations to provide recognition and support for the young carer's role. The Young Carers Program aims to improve the well-being of young carers by relieving stress, anxiety and hopelessness, increase self-esteem, and decrease stigma by connecting with other young carers, hence decreasing isolation. The goal of this proposed participatory research is (1) to explore the experience of what it is like to be a young carer and (2) to assess the impacts of the Young Carers Program (YCP) from the perspective of YCP members. To achieve this goal, we will conduct a participatory photovoice project with young carers. Photovoice is a method that combines photography and storytelling to explore a particular issue, in this case the experience of young carers. YCP members will be invited to participate in a project over the course of 3 months to creatively share their story and shine light on some initial impacts of the YCP program. The findings from this research will raise awareness about young carers as well as identify ways community organizations can support young carers.

# CURRENT PROJECTS CONT.

**Project Name**

Child Reporters Initiative

**Project Coordinator**

Lalatendu Acharya

**Project Location**

Koraput/ Orissa, India

**Age Group Involved in Research Decisions**

Children (10-14 years)

**Project Description**

Child Reporters Initiative (CRI) is framed within the concept of child participation and the guiding philosophy to create a platform for children's voices and listen to them. Using participatory methods, involving local community volunteers, the CRI is led by children studying in different government and other schools in Koraput, a district in the Orissa, India home to predominant tribal populations. The child participation project was conceived in 2004/5 is continuing with different iterations and programmatic adjustments.

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**Project Name**

KLIK

**Project Coordinators**

Professor Tineke Abma

Janine Schrijver

Femke Boelsma

**Project Location**

Rotterdam, The Netherlands

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

**Project Description**

In the Netherlands a project named KLIK (an acronym which translates into Children Learn Inventive Power) started in July 2015. In KLIK photos play an important role to help children to explore their life-style and their neighbourhood. KLIK therefore stands for the click of the camera as well as for the click between the child and his/her environment. KLIK is a participatory action research project, which aims to improve the health and resilience of children living in a disadvantaged neighbourhood. Ideas and plans are developed to promote the health of children through partnerships and participation of children and other stakeholders/partners from the neighbourhood. The experiences of children are the base of the bottom-up health promotion, and photography is the common thread throughout the process.

KLIK employs activities on three levels: home, school and the neighbourhood.



**Project Name**

Lost in Transition: An investigation into children's understandings and experiences of wellbeing during the transition to school

**Project Coordinator**

Jennifer Fane

**Project Location**

Adelaide, Australia

**Age Group Involved in Research Decisions**

Children (5 years and under)

**Project Description**

While there are numerous international conceptualisations and measures designed to identify or assess young children's wellbeing, no current frameworks or instruments have taken young children's voices and experiences of wellbeing into account. As the UNCRC upholds children's right to have their opinions taken into account in matters that affect them, this project seeks to understand how young children experience and understand wellbeing, and if their conceptualisations differ from those of adults. This project has two stages, a preliminary study which sought to identify how young children experience and understand their own wellbeing, and a longitudinal study which will track child wellbeing using child identified indicators of wellbeing across the transition to school. Both stages of the project have used emoji as a child-centred visual research method to elicit children's voices within childhood research.

# CURRENT PROJECTS CONT.

**Project Name**

Talking Circles

**Project Coordinator**

Marilyn Casley

Kerry Smith

**Project Location**

Various, Australia

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

**Project Description**

The Talking Circles were designed to encourage children to ask questions about their lives and how they can make a difference for themselves, each other and their community (Carmel & Casley 2014). They are based on thinking about learning as a process of awareness and community building, providing opportunities for conversations with children about their ideas and perspectives. The process is underpinned by the notion of generative listening (Scharmer, 2009)- listening to oneself, listening to others , and listening to what emerges from the group. Through the process of listening to and talking with one another, children made connections and established relationships with each other and the adults involved. The findings from the Talking Circle project illuminated thinking about the knowledge and skills required to build relationships between adults and children and between children.

It has been proposed to use Talking Circles as an evaluation tool to gather children's perspectives on programs and delivery of services for them.



**Project Name**

Disaster, Poverty and Coping

**Project Coordinator**

Revathi N. Krishna

**Project Location**

Chennai, India

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

Youth (15-25 years)

**Project Description**

People living in poverty are particularly vulnerable to the effects of disasters, with long-term economic, health, and mental health consequences (Dercon, 2004; Carter, Peter, Tewodaj, & Workneh, 2007; Galea, Tracy, Norris, & Coffey, 2008). Children exposed to disasters can be particularly vulnerable and have different needs from adults due to many factors including their age (Peek, 2008), loss of perceived safety, an inability to make sense of the world, and loss of important attachment figures (Norris, Friedman, & Watson, 2002).

Recently, I conducted a systematic review on how children and families living in poverty in the Asia Pacific region cope with disasters. The review (currently under consideration at a journal) highlighted the lack of inclusion of children as active participants despite the established evidence to include them in the disaster risk reduction (Ronan, Crellin, & Johnston, 2010; Ronan & Johnston, 2005; Wachtendorf, Brown, & Nickle, 2008) and related policy and planning dialogues. Only three studies of the 26 studies included for the systematic review included children as participants. Hence, the aim of this PhD research will be to understand the experience of children and families living in poverty in preparing and coping with disasters. It is their active participation that will shape the project and provide an understanding of their experience and answer some of the research questions laid out for the project.

The specific research questions I aim to answer in my PhD are:

1. How do families living in poverty teach / talk to their children about disasters, preparedness and recovery?
2. What are children's experiences of disasters when they are living in poverty?
3. What are the coping strategies that these children use to prepare, cope and recover from disasters?
4. Would interventions that focus on building problem solving skills and resilience generally in children (including discussion on disasters) would aid children in coping with disasters more effectively?
5. What are the active ingredients in a resilience building intervention that aides children who live in poverty to cope with many life adversities including disasters?
6. What are the differences between children and families experience in preparing and coping with disasters while living in poverty in India and Australia?

# CURRENT PROJECTS CONT.

**Project Name**

Children as contributors

**Project Coordinator**

Lisa Gibbs

**Project Location**

Victoria, Australia

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

Youth (15-25 years)

**Project Description**

Our aim is to explore the extent and nature of child contribution in their daily lives and how this is experienced at different ages. Children will be co-researchers in a partnership study with local schools, sporting clubs and ABC children's program - Behind the News to co-generate new findings and identify new directions for promoting child wellbeing and resilience.

Specifically, we are planning to:

1. Work with Behind the News to synthesise the results of their first Happiness Survey
2. Conduct research workshops with children in 4 diverse partner schools (bush, beach, city & suburbs) and youth at 2 partner sporting clubs with diverse membership to see how they respond to the survey results, and identify additional survey questions to provide insights into child experiences as contributors in their daily lives
3. Literature review to inform framing of the extra questions and analysis of results
4. Provide Behind the News with the child and evidence-informed additional questions for their 2017 survey.
5. Engage children in the partner schools and sporting clubs in analysing and reporting the new survey results (e.g. through the Behind the News Rookie Reporter segment)
6. Engage children/youth in partner schools and sporting clubs in the development of a proposal for change that will guide further work in promoting child wellbeing and resilience in Australia and offsetting the impact of adversity.

**Project Name**

Well-being of 8 to 10 year old children

**Project Coordinator**

Emilie Achermann

Theres Bauer

**Project Location**

Zurich, Switzerland

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

Youth (15-25 years)

**Project Description**

The project is realized with a group of ca. 20 students at the Zurich University of Teacher Education. The project looks to answer the following questions: What do children understand by well-being? When do they feel well? What contributes to their well-being? Can they contribute actively to feeling well?

The project is based on the photovoice method: Children are given disposable cameras and asked to take pictures of situations and locations where they feel well. The pictures then serve as stimuli for qualitative interviews carried out by the students. The interviews are transcribed and analyzed. The results are communicated to other students of the Zurich University of Teacher Education and to teachers.

Until further notice the project takes place every year.

# CURRENT PROJECTS CONT.

**Project Name**

(Co) Producing Help-Seeking Narratives with Children of Parents with Mental Illnesses

**Project Coordinator**

Brenda Gladstone

**Project Location**

Toronto, Canada

**Age Group Involved in Research Decisions**

Children (10-14 years)

Youth (15-25 years)

**Project Description**

Recent estimates suggest that 12.1 % of all Canadian children under 12 have a mentally ill parent. In this complex and under-served area little is known about how young people manage the challenges they encounter and respond to services they do receive, or how they would like to be supported in this context. We studied children's help seeking narratives using an arts-based participatory research approach posited to foster critical reflection and facilitate expression and communication about (often sensitive) aspects of experience. A second objective was to examine how young people acquire further competencies and skills through guided participation and active engagement in the research process, documenting the process of arts-based knowledge production throughout the study.

The study was designed to go beyond identifying children's problems, to examine possible solutions they identify as important and to provide information that would benefit knowledge users and decision makers because their views would help to determine how to do things differently in practice. Methods: Ten young people (13-18 yrs.) currently receiving community-based mental health services participated in the project. Participants worked work as a group longitudinally over the course of the study, guided by adult facilitators to clarify study objectives and research questions; produce 2-3 minute digital stories consisting of visual imagery and a sound-track, including voice-over narration; analyze study data; provide feedback on project findings; and, recommend knowledge translation strategies to reach and engage particular audiences. Participant observation and informal interviewing methods enabled documentation of project activities and participant engagement in the research process. Results: In addition to gaining skills through the digital storytelling process, young people want their stories to be used to educate and provoke audiences. They are keen to think about how their stories might impact others and embrace the idea that knowledge has the power to incite change. At the same time, participants are fully aware of the risk associated with sharing stories. The pity look for example, articulates an unhelpful response by other people to stories of vulnerability. The (re) action of others is consequential for young people who interpret responses like this as people shoving off what you are saying, deciding it may be better not to talk about the challenges they experience.



**Project Name**

Inclusive Spaces

**Project Coordinator**

Tobias Buchner

**Project Location**

Vienna, Austria

**Age Group Involved in Research Decisions**

Children (10-14 years)

Youth (15 years)

**Project Description**

Recent research has shown that social participation remains one of the main challenges for inclusive education. "Inclusive Spaces" tries to tackle this problem. Building on the 'insider perspectives' of students, we try to generate knowledge that contributes to fostering social cohesion at schools. The project follows a strong participatory approach. Two theoretical concepts are key to the research work at three participating schools: social space and difference. We understand space as being produced within interactions by subjects. In these spaces, children and adolescents perform identities, often with reference to 'lines of difference' (e.g. dis/ability or fe/male), and organise the in- and exclusion of subjects.

Research is organised in a series of workshops (ca. 12 – 14 meetings) with heterogeneous groups of students at the lower secondary level (aged 10-15) attending each school. The series follows a two-part structure: in the first part, young persons explore spaces within their schools (and what differences might be relevant in these spatial contexts) through visual and other qualitative methods, such as photo-voice interviews, mapping and focus groups. Data gathered in this phase are analysed by adult researchers and shared with the young people involved. Interpretations by the adult researchers are discussed with and validated by the participating students. This research and thinking forms the basis for the second phase of the workshops. After reflecting on the first phase, students identify topics they are interested in. In a next step, they are equipped with research skills and learn how to set up and conduct (small scale) qualitative and/or quantitative interview studies. Supported by adult researchers, students conduct their own projects on their topics of interest. At 'transfer platforms', young and professional researchers jointly present the young persons' projects as well as results of the first phase of workshops.

# CURRENT PROJECTS CONT.

**Project Name**

Research Center for Integrated Disaster Risk Management

**Project Coordinator**

Andrea Vasquez

**Project Location**

Santiago, Chile

**Age Group Involved in Research Decisions**

Children (11-14 years)

Youth (15-18 years)

**Project Description**

A part of CIGIDEN (Research Center for Integrated Disaster Risk Management) we created an interdisciplinary research project (composed by geographers, psychologists and engineers), in order to know the perspectives of children about their school evacuation process among children aged 11-18 with previous experiences of drills and natural disasters. The main motivation of this research was to explore the interaction between children and their environment under extreme conditions (Fondecyt 1141187).

We worked for three years with a school community located in the the city of Iquique, located as well in north of Chile that was affected by Pisagua earthquake (8.2 Mw). Colegio Ingles trusted in our research project and allowed our interdisciplinary research team to work with them in a collaborative way, in which the transfer of results to the school community was part of the research goals.

The first year of the project (2014) we made many activities for engaging the school, such as: organizing meetings, showing them the goals and the impact of the research in their school evacuation plan. This presentation was also shared with other local stakeholders from emergency management, in order to share the research located at Colegio Ingles with other schools in Iquique Chile.

In the second and third year of research (2015-2016) we worked closely with a sample of leader children aged 11-18 from Colegio Ingles, and we applied focus group in which we discussed about their experience in Pisagua earthquake, the obstacles identified by them in their evacuation route and the recognition of safe places in the context of evacuation from the school.

In the third year (2016) we focused on the collective dimension of evacuation and as researchers, we designed some educational modules for responding to the questions stated by them in the second year, about: (i) how to face situations of collective panic during an evacuation, (ii) how to provide help to injured people in the evacuation route, (iii) how to negotiate the obstacles existing at the evacuation route.

In this last year, we also invited the children to collaborate with us in the creation of a book of recommendations for improving the evacuation process of schools, based on their own experience and knowledge, and then share it with other children allocated in other schools around Chile and overseas.

The materials of the book were prepared by themselves, with some guidelines provided by the research team. For instance, the book is composed by pictures taken by themselves using devices (Ipad) provided by the research team. They selected the pictures for showing the most important (defined by themselves) obstacles they face in their evacuation route. Also a list of recommendations for improving their evacuation process was shared and discussed in a participatory map, that was made as a collective activity, in which they could identify and allocate the obstacles and recommendations about their evacuation process.

Currently, the research team is working on the design of the book for sharing it with other school communities in 2017.

**Project Name**

Giving voice to the children with rare diseases

**Project Coordinator**

Suja Somanadhan

**Project Location**

Dublin, Ireland

**Age Group Involved in Research Decisions**

Children (14 years and under)

Youth (15-25 years)

**Project Description**

This project is designed to enable children, young people and their families living with rare diseases to express their experience of living with disease and help to identify the factors that enhance, inhibit and impact on their lives through a range of creative arts.

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**Project Name**

Children's Voices in Curriculum

**Project Coordinator**

Sharon Eggins

**Project Location**

Melbourne, Australia

**Age Group Involved in Research Decisions**

Children (5 years and under)

Teachers

Parents

Community workers

**Project Description**

I am not a researcher, I am a practitioner in community services working with 4 and 5 year old school transition curriculum. I am investigating children's participation in this sector and am hoping to gain insights from the networks wealth of experience. I am also applying for a Churchill Fellowship to investigate participation methods used with young children (6 and under).

# CURRENT PROJECTS CONT.

**Project Name**

Listening to Children: Important places in nature

**Project Coordinator**

Ali Black

**Project Location**

Maleny, Australia

**Age Group Involved in Research Decisions**

Children (5 years and under)

Children (6-9years)

Researchers

**Project Description**

Researchers Dr Ali Black and Dr Gail Crimmins, with pre-service teachers and Mary Cairncross Scenic Reserve Volunteer/Guides use a listening framework (The Mosaic Approach) to listen to and gather children's perspectives as they experience the natural world at the Reserve and as they engage with the Discovery Centre's interpretation materials and activities. This child-centred and child-led project offers a toolkit of evaluative and practical strategies which researchers, pre-service teachers, MCSR volunteer guides and staff will use during the project (and into the future) to gather information with children about how they are thinking about, interpreting and responding to nature and related conservation experiences.

These methods include:

- observation/children telling stories/sharing narrative accounts
- child conferencing/conversations
- children taking photos
- tours directed and recorded by children
- children's map-making and arts-based representations.

Data gathered during project phases focus discussions and professional development between researchers, pre-service teachers, MCSR volunteer guides and staff. This collaborative discussion and reflection on data will consider aspects such as intergenerational stories, children's lived experience, perspectives and participation, and implications for practice. Pedagogical documentation will be collectively created to highlight shared learning and take the form of learning stories, case-studies and displays.

Documentation will be derived from observations, discussions and reflections. This documentation will be professionally displayed at the Discovery Centre and will support wider community identification of the Discovery Centre's child-centred environmental education priorities, and children's and adult's perspectives and experiences of nature. Using the generated research data, additional child-centred educational experiences will be suggested and designed for use by the Reserve and Discovery Centre.



**Project Name**

Working towards promoting the occupational participation of children with disabilities through participation action research

**Project Coordinator**

Tanya Benjamin

**Project Location**

Vellore, Tamil Nadu, India

**Age Group Involved in Research Decisions**

Children (10-14years)

Youth (15-25 years)

Researchers

**Project Description**

This project is a partnership between the Department of Health and Rehabilitation Sciences at Western University, Canada and the Community Health Department of Christian Medical College, Vellore, India. This is a four phased participatory action research (PAR) project with children with disabilities, aged 10 to 18, in a rural South Indian context.

PAR is a process where researchers collaborate with community members within the research and action processes, facilitating dialogue and shared reflection on issues affecting them to guide social change. There is a dearth of research in India that involves children with disabilities as research collaborators to explore their experiences, especially related to their occupational participation, referred to as daily activities that they need and want to do as individuals and collectives.

This project aims to explore perspectives of children with disabilities regarding their occupational participation using a participatory digital methodology (digital storytelling or participatory video) to enhance engagement. Phase one will involve strengthening collaboration with local researchers, identifying specific village(s) and recruitment; phase two will involve working with 6-9 children to collaboratively choose a specific research focus and a specific participatory digital methodology; phase three will involve the children exploring the identified research agenda using a digital methodology, encompassing either individual production of digital narratives (digital storytelling) or collective production of a video (participatory video making), and setting priorities for action; phase four will encompass mobilizing action. Overall, phases 1-3 will be for 6-8 months, and children with disabilities will be involved in approximately 16-21 group meetings, which will include child friendly group activities and group discussions; and phase four will be a continuous phase involving mobilizing action and addressing social change.

Through this PAR that employs a participatory digital methodology, we aim to promote the inclusion of children with disabilities both within research and within society.

# CURRENT PROJECTS CONT.

**Project Name**

NEAR YOUTH to Advise Baltimore City Anti-tobacco Coalition

**Project Coordinator**

Fernando Wagner

**Project Location**

Baltimore, USA

**Age Group Involved in Research Decisions**

Children (6-9years)

Children (10-14years)

Youth (15-25 years)

Parents

Researchers

Health workers

**Project Description**

Tobacco use is still the top cause of preventable loss of life, with unacceptable disparities by income and education groups in Baltimore. But this can be solved through adequate programs and policies. None of which can occur without clever community involvement.

An estimated 20 Baltimore City middle and high school students will engage in creative and interactive activities that will nurture their innate sense of social justice and develop the skills necessary to improve their communities, particularly about tobacco prevention and control. These youth will receive training about the scope, impact, and public health alternatives to tobacco-related problems, and then will create working teams that will meet monthly or more often as needed, acquire skills needed to critically analyze the situation in their communities and develop anti-tobacco policy recommendations likely to be endorsed by other youth to help address the main health disparities.

These recommendations will be presented to the Baltimore City Anti-Tobacco Coalition to enhance programs and policies with the ultimate goals of promoting wellbeing and social justice. The significance of the project is that the recommendations provided by these young people can be useful to help frame policy alternatives to eliminate tobacco and other health disparities issues.

**Project Name**

(Des) embarazo: participatory action research with adolescents to prevent pregnancy

**Project Coordinator**

Hayda Alves

**Project Location**

Rio das Ostras, Rio de Janeiro, Brazil

**Age Group Involved in Research Decisions**

Children (6-9years)

Children (10-14years)

Youth (15-25 years)

Parents

Researchers

Health workers

**Project Description**

Adolescent pregnancy (AP) occurs in individuals aged between 10 to 20 years. In less developed countries, it becomes a public health problem given its magnitude and association with generational poverty, health inequities, as well as vulnerabilities that compromises opportunities and choices of girls. Despite these findings, the outreach of conducted research regarding this matter set forth outcome limits, for lacking methods that value teenagers and engages them in building of changes from open and informed choices. Therefore, it has become essential to design researches and interventions guided by the world's insight and their aim subject: the teenagers.

In this way, this project aims to reduce teenage pregnancy from the interventions based on PRECEDE-PROCEED model. The work has been developed since 2015 in a municipality in the state of Rio de Janeiro, Brazil. It is a participatory research that adopts different quantitative-qualitative methods, such as: epidemiological information analysis, interview participant observation, conversation circles, focal group led by the method of world cafe. In addition to adolescents residing in the municipality, it also involves health workers, members of the school community and managers.

So far, a social and epidemiological diagnosis was carried out with a profile of the births of teenage mothers; And part of the educational and organizational diagnosis. These data will guide practices in popular health education directed at adolescents and young people. The diagnostic phase highlighted important information such as: increased cases of pregnancy among children under 14 years old, high levels of multiparity, fragility in the prenatal care of these mothers, difficulties in access to schooling and work. In the educational diagnosis, some pre-disposing, facilitating and reinforcing factors associated with AP were identified.

This phase of the study points to the linkage of the theme with the lack of future life projects for adolescents and young people. It also demands the confrontation of gender issues, the use of preventive methods for sexually transmitted infections and pregnancy, as well as the enjoyment of sexual and reproductive rights. It also revealed desires and challenges of the school community in dealing with the issue, which emerges for this group as a sign of the experience of other vulnerabilities by adolescents and young people. This research has been deepened, as well as designed interventions to be operationalized through peer education.

# CURRENT PROJECTS CONT.

**Project Name**

What life is really like for children who live with chronic pain?

**Project Coordinator**

Siobhan O'Higgins

**Project Location**

Ireland

**Age Group Involved in Research Decisions**

5-12 year olds

**Project Description**

Prime-C (longitudinal study of prevalence, impact and economic cost of chronic pain among 5-12 year olds in Ireland) found 1 in 10 children self-identified as having chronic pain. These children experience a number of things differentiating them from their peers, ranging from practical implications - absence from school and difficulty with writing - to psychological implications - fear and social isolation. The value of adding PHR as a further layer to the PRIME-C study became clear as the children shared their pain stories, which made us aware that not only were children not telling adults about their pain but, when they did tell their teachers, the reaction from staff in the primary schools was not necessarily the best. For example, children reported that they were told to drink water and/or put their head down on their desks, or wait away from their classmates for someone to take them home, so isolating and differentiating them from their peers.

These findings stimulated us to work together with the children to explore how best to create an intervention for teachers to raise awareness of paediatric chronic pain and possibly more effective management strategies. A first step in this approach was to invite 15 children who live with chronic pain and their families to a PHR workshop which turned into a picnic on a sunny Saturday afternoon in Dublin, as a central location. In this way we overcame one of the challenges of working with children out of the school setting, i.e. securing parental consent and acquiescence to transport their children to an event. The PRP workshop involved asking our young participants to individually to share their perceptions on issues that affect them on a daily basis either in drawings or words on pieces of coloured paper. This first step is crucial, as from past experience and with a commitment to work with 'the experts' (i.e. the children living with chronic pain), researchers' and adult ideas may well be different from the lived reality. The children then collated all their ideas into themes and choose the most important area that they would then explore in more detail as: "being part of school life". With that issue in the centre, they developed a 'Web of Ideas' about how to support children with chronic pain to participate more fully in primary school life.

The ideas identified by the children became the basis of an awareness raising exercise lead by the children. The children on our PHR picnic decided to make videos to illustrate how chronic pain impacts on them and some ideas on how to improve their ability to 'be part of school'. Using their parents' phones they went to work. This process is still on-going, with work currently focused on finalising this educational and awareness-raising video for teachers and primary schools. We plan to release the video on YouTube for all the families involved in the project and a wider audience including the 39 schools involved in PRIME-C.



Using the video as a starting point, we hope to work with principals and teachers to create a short intervention to raise awareness and help develop school specific protocols during teacher training programmes in the various teacher training colleges. This will ensure that protocols exist to support children who live with chronic pain within their school community. It is known that 80% of academic achievement is due to the teacher-child interaction (Thackore, 2016). If children with chronic pain can remain engaged within the learning environment with support of teachers, their potential to thrive and fully participate in post primary school will be enhanced.

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**Project Name**

HBSC

**Project Coordinator**

Colette Kelly

**Project Location**

48 countries

**Age Group Involved in Research Decisions**

Children (10-14years)

Youth (15-25 years)

Researchers

**Project Description**

Health Behaviour in School-aged Children is a cross-sectional survey run in collaboration with WHO Europe. It examines health, health behaviours and the social context of health for children aged 11, 13 and 15 years.

# CURRENT PROJECTS CONT.

**Project Name**

Kids in Action

**Project Coordinator**

Manou Anselma

**Project Location**

Amsterdam, Netherlands

**Age Group Involved in Research Decisions**

Children (6-9years)

Children (10-14years)

Researchers

**Project Description**

In the 'Kids in Action' study we use Youth-led Participatory Action Research (YPAR) to involve children from a low socioeconomic neighborhood in developing, implementing and evaluating inter-ventions aimed at the promotion of a healthy lifestyle. The Kids in Action study is conducted in col-laboration with all four primary schools in one neighborhood. At each school a participatory (YPAR) group was formed consisting of six to eight child-researchers aged 9-12 years and one or two aca-demic researchers. The YPAR groups are facilitated by an academic researcher, but there is equal collaboration in decision making with the children. During three school years (2016-2019), the YPAR groups meet (bi)weekly to work on the study.

During the meetings, the YPAR groups are involved throughout the process of intervention devel-opment. To structure the intervention development process and improve the evidence-base and po-tential effectiveness of interventions, Intervention Mapping (IM) is added to the process of YPAR. For example in the first step of IM, a participatory needs assessment was conducted in which chil-dren also conducted their own research. Based on this needs assessment objectives were derived that needed to be reached in the community. Four program goals were determined: 1) children participate in more outdoor play 2) more children join organized sports 3) children drink less sugar-sweetened beverages and more water 4) children eat less unhealthy snacks.

Together with the YPAR groups intervention ideas and implementation plans were developed. In col-laboration with community partners interventions were implemented. Currently we are in the final year of the project in which we evaluate already implemented interventions and are also still in the ongoing process on working on new intervention ideas.

Alongside the YPAR process a process and effect evaluation is conducted in which we monitor the YPAR process, collaboration with community partners, empowerment and the developed interven-tions (all process evaluation), dietary behavior, sedentary behavior, physical activity and physical fitness (effect evaluation).

**Project Name**

The ruling of weight: An institutional ethnographic exploration of students' weight bias experiences

**Project Coordinator**

Alexa Ferdinands

**Project Location**

Edmonton, Canada

**Age Group Involved in Research Decisions**

Youth (15-25 years)

Researchers

**Project Description**

Weight bias refers to the tendency to negatively judge individuals based on their weight. Pervading all domains of life, it can result in serious physical, mental, and social health consequences. Indeed, weight bias can reinforce weight gain by triggering unhealthy coping behaviours, such as binge eating. In Canada, one-quarter of children have excess weight, increasing their vulnerability to weight bias, particularly in settings like schools, where they spend a significant portion of their day-to-day lives. Weight bias manifests in myriad forms in schools, such as weight-related bullying, social exclusion, and differential treatment by teachers. Weight bias reduction strategies to-date have predominantly focused on individual attitudes and behaviours, neglecting socio-structural forces. A bird's eye view of the situation, which accounts for these broader forces, can enhance our ability to identify effective levers for social change.

As such, the aim of this research is two-fold: 1) To explicate the social organization of students' weight bias experience in Edmonton public schools; 2) To create space for the empowerment of research participants in countering weight bias. I will use institutional ethnography (IE), a method of inquiry that elucidates how everyday actions are coordinated across time and space, without our knowing, by ruling relations. With its critical theoretical underpinnings, IE questions the taken-for-granted, such as the thin ideal. This research takes the standpoint of youth with obesity, beginning with their quotidian actualities. With the youth, I will conduct individual interviews and focus groups to map out, chronologically, their experiences of weight bias in schools across the trajectory of their lives. To move beyond the local and particular into the translocal, I will examine text-mediated forms of social organization (e.g., school policies, curricula). I may also be led to speak with school staff and parents to better understand these social relations. In this process, I will collaborate with youth with obesity to name and shape a "youth jury" to advocate against weight bias. There is potential for this jury to be bridged with Obesity Canada's Public Engagement Committee, which is currently confined to adult representation. Overall, this research aims to unveil a map of the ruling relations of weight bias. Cultivating a concrete understanding of how weight bias is socially organized can provide us with a starting place to change dominant weight-related ideologies.

# CURRENT PROJECTS CONT.

**Project Name**

LIKE (Lifestyle Innovartions based on youth's Knowledge and Experience)

**Project Coordinator**

Meredith Overman

**Project Location**

Amsterdam, Netherlands

**Age Group Involved in Research Decisions**

Children (10-14 years)

Researchers

**Project Description**

LIKE is a 5-year program designed to stimulate a healthy lifestyle among 10-14-year-old adolescents with a low socioeconomic position in three neighbourhoods in Amsterdam East. In co-creation with adolescents, their parents and other key stakeholders, opportunities for a healthier lifestyle in Amsterdam East are explored. The overall objective of this research project is to motivate, enable and empower adolescents (10 – 14 years old) and their parents to take action in the interest of adopting and improving healthy habits and to tackle overweight and obesity at a young age. Specifically, this project aims to develop, implement and evaluate innovative interventions at the level of family, school and neighbourhood, based upon a detailed insight into the characteristics of the population at stake.

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**Project Name**

Self organisation from children in Colombia

**Project Coordinator**

Nikias Obitz

**Project Location**

Bogota, Colombia

**Age Group Involved in Research Decisions**

Children (6-9 years)

Children (10-14 years)

Youth (15-25 years)

Community Workers

**Project Description**

Childrens view about participation in a selforganisation in Colombia



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<b>Book Chapters</b>	<p>Gibbs, L., Marinkovic, K., Black, A. L., Gladstone, B. M., Dedding, C., Dadich, A., O'Higgins, S., Abma, T., Casley, M., Cartmel, J. and Acharya, L. (2018). Kids in Action - Participatory Health Research with Children. In M. Wright and K. Kongats. (Ed), <i>Participatory Health Research: Voices from Around the World: Springer</i>.</p> <p>Black, A.L. and Crimmins, G. (in press, 2019). Playwork in the Mary Cairncross Scenic Reserve. In J. Cartmel (Ed), <i>Crossing Boundaries with Playwork Practice</i>. UK: Routledge.</p>
<b>Presentations</b>	<p>Casley, M., Smith, K., Black, A.L., Grace, R., Dadich, A., Cartmel, J. (2019). Rethinking Child and Youth Participation in Policy Making and Practice. <i>2019 Child Aware Conference</i>. Brisbane, 16-17 May, Brisbane Convention and Exhibition Centre.</p>
<b>Research</b>	<p><b>Think Big</b>  <b>Kids in Action members:</b></p> <ul style="list-style-type: none"> <li>• Prof Lisa Gibbs</li> <li>• Prof Rona Campbell</li> <li>• Prof Mahia Saracostti</li> <li>• Katitza Marinkovic</li> </ul> <p><b>Participatory research: how ethics committees in different nations include the voices of children and adolescents toward democratic knowledge.</b></p> <p><b>Coordinator:</b></p> <ul style="list-style-type: none"> <li>• Hayda Alves, Adjunct Professor, Institute of Humanities and Health , Fluminense Federal University – Rio das Ostras (Brazil)</li> </ul> <p><b>Partnerships with members of Kids in Action:</b></p> <ul style="list-style-type: none"> <li>• Payam Sheikhattari - Director, the Prevention Sciences Research Center, Morgan State University (United States)</li> <li>• Lisa Gibbs – Director, Jack Brockhoff Child Health and Wellbeing Program, Melbourne School of Population and Global Health, University of Melbourne (Australia)</li> <li>• Irma Brito, Adjunct Professor, Nursing School of Coimbra (Portugal)</li> <li>• Katitza Marinkovic, Jack Brockhoff Child Health and Wellbeing Program, Melbourne School of Population and Global Health, University of Melbourne (Australia)</li> <li>• Ann Dadich, Western Sydney University</li> </ul> <p><b>Others partnerships:</b></p> <ul style="list-style-type: none"> <li>• Carlos Rodrigues Brandão, Emeritus Professor, Instituto of Philosophy and Human Sciences, UNICAMP (Brazil)</li> </ul>
<b>ICPHR Annual Working Meetings</b>	<ul style="list-style-type: none"> <li>• 2019, Baltimore, USA.</li> <li>• 2018, Edmonton, Canada.</li> <li>• 2017, Limerick, Ireland</li> <li>• 2016, Malmö, Sweden</li> </ul>

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Articles in writing	<p>Exploring Terms for Children and Young People: A discussion paper Buckle, N; Gibbs, L; Kroll, T; Shier, H; Somanadhan, S.</p> <p>What does participatory mean in child participatory healthcare research?</p> <ul style="list-style-type: none"> <li>• Prof. Lisa Gibbs University of Melbourne</li> <li>• Dr Lalatendu Acharya Purdue University</li> <li>• Adjunct Prof. Hayda Alves Fluminense Federal University</li> <li>• Dr Jana Fried Coventry University</li> <li>• Dr Kwabena Frimpong-Manso University of Ghana</li> <li>• Dr Brenda Gladstone University of Toronto</li> <li>• Ms Katitza Marinkovic University of Melbourne</li> <li>• Ms Revathi Nuggehalli Krishna Monash University</li> <li>• Dr Suja Somanadhan University College Dublin</li> </ul> <p>Position Paper: Kids as Global Agents of Change. Authors (in alphabetical order, final author list to be confirmed):</p> <ul style="list-style-type: none"> <li>• Arif Mahmud</li> <li>• Dr Christinne Dedding</li> <li>• Gia Gner McGinnis</li> <li>• Dr Hayda Alvez</li> <li>• Dr Irma Brito</li> <li>• Jummai Apata</li> <li>• Katitza Marinkovic</li> <li>• Keitra Thompson</li> <li>• Liner Máuier Buendinelli</li> <li>• Matthias von Witsch</li> <li>• Shannon Sánchez-Youngman</li> <li>• Dr Suja Somanadhan</li> <li>• Ulysses D. Archie Jr.</li> </ul>
Building our vision	<p>Visual Manifesto: who we are and what's our mission?</p> <p>Project booklets (2)</p> <p>Survey on terminology about children and adolescents</p> <p>Resource repository in ICPHR Website</p> <p>Supporting kids' action for climate change</p>
Events	<p>UCD CHiLD Research Centre Annual Conference- to celebrate Universal Children's Day Title: "Children's Rights for a Healthy World" 14th of November 2019- Venue University College Dublin, Ireland.</p>