

# **Promoting New Zealand children's active participation in healthcare**

**Amanda Scheibmair**  
(née van Rooyen)

**Margaret May Blackwell Travel Fellowship**  
**2015/2016 Report**



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# Margaret May Blackwell

Excerpt taken from *Margaret May Blackwell Travel Study Fellowship: Instructions and information for applicants 2015/2016*

Margaret Blackwell was born in Kaiapoi in 1907. She completed her early education in Kaiapoi and her secondary education at Christchurch Girls' High School and Colomba College in Dunedin. Later in Dunedin she trained and qualified as a Karitane Nurse. Returning to Kaiapoi she was active in the Girl Guide Association becoming District Commissioner. She was also a keen sportswoman, particularly in tennis and in golf.

In the mid-1930s Margaret Blackwell travelled to England, and in London studied pre-school education under the direction of Susan Isaacs, who at that time was a leader in the subject. During the Spanish Civil War Margaret Blackwell helped escort refugee children to England.

Her concern for the safety of children and moving them from war zones was shown again when after the declaration of the Second World War in 1939 she helped escort a large group of children by ship from England to Canada. During the period of the War she remained in North America for about five years, furthering her experiences and training in early childhood education at the Toronto University in Canada, and at Colombia University in New York.

On her return to New Zealand after the War, she settled in Auckland where she worked as a child psychologist at the Auckland Hospital for many years. She was an early advocate of parents staying with their young children during periods of hospitalisation. She was an early advocate of finger painting as a good therapy for children. During this time she became very involved with the Inter-church Counselling Centre, with the Telephone Life Line Service, and with the Friends of the Service whose purpose was to raise funds.

Margaret Blackwell died in Sacramento, California in 1980 after a period of hospitalisation in San Francisco and Sacramento.

The bequest of Margaret May Blackwell makes available an annual fellowship to enable a nurse working in early childhood health to travel overseas to gain further knowledge and subsequently disseminate that information back in New Zealand for the benefit of early childhood health in New Zealand.

This is a prestigious award covers travel and accommodation for overseas travel. It is open to registered nurses who are practising in the public, private and voluntary sectors of early childhood health or registered nurses who are teaching at a tertiary level in the subject.

## Correspondence

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# Introduction

Health professional's recognition of the importance of children and young people's participation in healthcare is gaining traction internationally, mostly driven by Article 12 of the United Nations Convention on the Rights of the Child (UNCRC). New Zealand ratified UNCRC in 1993 but is yet to fulfil its obligations as detailed in the convention, specifically Article 12 which relates to children's participation (Ludbrook, 2000; UNCRC Monitoring Group, 2013). Article 12 specifies that children have a right to participate in decision-making processes regarding matters that are important to them and that may influence their lives (UNICEF, 2014b). In healthcare, children's participation extends from being involved in macro decision-making processes regarding health policy and service development to being involved in micro decision-making processes regarding personal health decisions and choices. It includes the right to seek, impart and receive information in a manner that is appropriate for their developmental level (Davies & Randall, 2015), and the right to express their views and having those views heard, respected and responded to (Hatton, 2014).

Children's active involvement in matters that are important to them, in particular their own healthcare, is one of their fundamental rights (UNICEF, 2014a). Adults however act as gatekeepers to children's rights, by both allowing and enabling children to enact their rights. There is international growth in the area of adults recognising their obligation to 'allow' children to enact their rights, but there is less understanding about how to enable or assist children to enact their right to participate in healthcare.

In addition to participation being a fundamental right, it can also increase children's feelings of autonomy, self-determination and control (I Coyne & Gallagher, 2011). This can result in benefits such as improved adjustment to hospitalisation and increased adherence to health treatment (I Coyne & Gallagher, 2011), and positively impact their personal development (Alderson, 2007; Lansdown, 2001). Albeit limited, research has also shown participation to have a significant influence on children's health outcomes (Dickinson, Wrapson, & Water, 2014; Doyle, Lennox, & Bell, 2013).

To support New Zealand children's participation in healthcare, particularly younger children below the age of 5 years, I travelled to the UK, Ireland, Belgium and Netherlands in search of new ideas, perspective, strategies and tools. With the assistance of the Margaret May Blackwell Travel Fellowship and Auckland University of Technology, I met with multiple key informants, mostly academics and health professionals, visited four paediatric hospitals and attended two conferences.

This report details my findings from my travels across Europe. Please note: The information included in this report is a result of informal conversations between myself and various academics and health professionals regarding ideas and resources to improve the participation of children in healthcare. Excluding the conference proceedings, key informants have reviewed and verified their 'perspectives/ideas' listed in this report prior to its publication. Additionally, it was not the intention of this report to detail the specifics of each idea, resource or strategy, rather to highlight them for New Zealand academics and health professionals to use and further explore so that they too may positively influence children's involvement in important health matters.

# London

## Professor Pricilla Alderson, University College of London

- PERSPECTIVE/IDEA – Prof. Pricilla Alderson
  - Even at a very young age children can express their own views about their needs. Even babies have an innate knowledge of the rhythms of human interaction and eye contact in ways animals do not do (Stern, 1977); and are able to indicate what they want and don't want. By 12 months they seem to understand what is right and wrong behaviour (Bloom, 2012). For example, Priscilla has worked with nurses at St Mary's Hospital who believe babies remember their mother's voices from when they were in the womb (Alderson, Hawthorne, & Killen, 2005). Another example of infants being able to express themselves is how they decide on and request feeding times.
  - Article 12 of the UN *Convention on the Rights of the Child* enshrines the child's right 'to form and express views'. However, rather than a right, this is an integral part of human nature from birth, to express oneself. Yet to many adults, children's views are only seen as valid if adults decide to 'verify' them or respect children's opinions, understanding and wisdom. The right to be heard and taken seriously (also part of Article 12) is then so highly qualified it might be seen as a privilege rather than a right (*Voices, Choices and Law: Weighing children's view in justice proceedings in Liverpool*, 2015).
  - Vulnerable children – our assumptions of vulnerability are not always accurate. Those who experience some form of adversity are often more competent, courageous and resilient than those who don't. Therefore some children in vulnerable groups may be more adept at asserting their rights to participation and to express themselves, and some supposedly non-vulnerable children may have serious difficulties. Vulnerability, for example in the case of Maori and Pacific Island children is often deeply seated in political and historical routines of culture, and in social interactions with people from other ethnicities.
- TRAINING PROGRAM - Newborn Individualized Developmental Care and Assessment Program (NIDCAP), Boston Children's Hospital.
  - According to the NIDCAP Program Guide 2015 an important goal of this educational and training program is to move from task-orientated care to relationship-based care, where infants are seen as active constructors of their own development. Listening to babies and understanding their expressions is a part of the on-going co-regulation process of infant and parent development (Als, 2016).

## Tricia Young, Director of Child to Child

- STRATEGY – early childhood development
  - Adaptation of 'Getting Ready for School'
  - Older children supporting and guiding younger children
  - Promotes on-time enrolment (which has been shown to increase the incidence of primary school completion)
  - Focuses on child protection, working with parents, and working with teachers to improve their competence

- STRATEGY – Radio program ‘Pikin-to-Pikin Tok’
  - Implemented by Child to Child in response to the outbreak of Ebola
  - UNGAI report
  - It is currently under review
  - 10 min film on the impact of Ebola
  - Documentary – broadcast in July on the radio program
  
- STRATEGY – London program ‘Hearing all voices’
  - For children who are disengaged from education, otherwise known as ‘Not in Education, Employment or Training’ (NEET)
  - Uses the Child to Child step approach
  - Action learning cycle – rather than learning things that don’t help them on a day-to-day basis or help them understand their place in the world, they learn helpful reflective information
  - Evaluation of this program should be completed in the next few weeks
  
- STRATEGY – Training healthcare professionals
  - Developing coaching skills to facilitate and support children, rather than just giving instructions or directions
  - Skills for active listening, open questions, space for children to be more reflective and learn how to ask questions, rather than adults spoon feeding children information
  
- STRATEGY – Story books
  - For both disabled and able-bodied children to promote the inclusion of children with disabilities and to sensitise able-bodied children to the trials and difficulties faced by disabled children
  - Buddying groups (able with disabled children)
  - Working closely with the Ugandan Society for Disabled Children

**Fiona Jones, Becki Moulton, Emma James, Suzanne Collin, Patient Experience Team, Great Ormond Street Children’s Hospital, London, United Kingdom**

- TRAINING PROGRAMME – Me First
  - <http://www.mefirst.org.uk/>
  - Used to improve the communication between health professionals and children and young people
  - Provides one-day master classes and workshops, videos, PDF documents and websites to help health professionals further develop their communication skills with children and young people
  - Gives clear information on why it is so important to develop good communication skills when working with children and young people, and outlines some of the barriers and challenges health professionals may face



Figure 1: Me First: Children and young people centred communication (Me first, n.d.)

- STRATEGY – Monkey Well-being
  - <https://www.monkeywellbeing.com/>
  - [Monkey Well-being is run by an independent organisation and is currently being trialled by GOSH](#)
  - Provides different Friends & Family Tests depending on the service (which are free for anyone to download). E.g. there is one available for walk-in centres, accident and emergency centres, minor injury units, GPs, dental practices, mental health services and community health services.
  - Posters and leaflets that are age appropriate for wards, classrooms or community services
  - Storybooks and activity guides to help children get ready and know what to expect when accessing health services. E.g. monkey has a blood test, Monkey goes to school, Monkey has an asthma attack, Monkey gets an injection... etc
  - Monkey is also kept at all health access points so that children can relate him to health, be able to access information and feel like they can ask questions if they have any.

- An evaluation of the 'healthy lifestyles' Monkey resources found them to be useful, engaging and informative for both children, teachers and other professionals, particularly the Monkey puppet, video clips and teacher resources. Two thirds of the responses to the national survey conducted as a part of this evaluation felt the resources helped children better understand what health services were available to them and which ones were the most appropriate ones to use (Medforth, Timpson, Greenop, & Lavin, 2015).

(Acknowledgements: Helen Sadler, Nick Medforth and Victoria Miller)



Figure 2: Monkey Wellbeing Resources (Mokey Wellbeing, 2016)

- STRATEGY – GOSH Friends & Family Test
  - Patient satisfaction and experience feedback – two separate forms; one for adults and one more appropriate for younger children that allows space for them to draw feedback.
  - Information is used to formulate reports for service areas on how and where to improve their services for their health consumers
  - It is paper based at the moment but there are some automated reports available and will be moving to electronic based feedback in the near future
  - Collects verbatim comments
  - Nurses can use comments in their portfolios
  - The implementation on the Friends & Family Test was a result of the Keogh and Francis Reports



Great Ormond Street  
Hospital for Children  
NHS Foundation Trust

**Hello!**

We would like to know what you think about our Ward/Department.

If someone you knew became poorly and had to go to hospital, would this ward be a good place for them to come to?

Please colour in the face that shows what you think

Yes

Don't know

No

What ward are you on?

---

How old are you?

---

For this visit, have you stayed one night or more?

☐ Yes    ☐ No

(Please turn over)

Write or draw what you think was **good**

Write or draw what you think was **bad**

(Please post this card in the post box on the ward. Thank you!)

Figure 3: Hospital children's feedback card (Great Ormond Street Hospital for Children: NHS Foundation Trust, n.d.)

- STRATEGY – Takeover Challenge
  - <https://www.childrenscommissioner.gov.uk/learn-more/takeover-challenge>
  - Organisations and individuals allow children to 'take over' adult roles
  - Puts children in decision making positions and encourages the professional organisations to hear their voices.
  - NHS organisations take part in the Takeover Challenge as they believe children should be heard and be able to take part in decision-making

- E.g. Takeover Challenge 2015 – two young people took over the role of Children’s Commissioner Anne Longfield for a day. They organised and filmed an interview with Anne about her work
- TOOL – New under 16 consent form
  - Asks health professionals if the ‘under 16 year old’ patient has the sufficient intellectual and emotional maturity to consent
  - If so, the ‘under 16 year old’ patient may consent to healthcare independent of their parents
- TRAINING PROGRAM – Junior doctors curriculum to include input from children
  - This training strategy was implemented by the Blackpool Trust, where Fiona Jones worked previous to GOSH
  - Junior doctor’s curriculum included a child run class about their experiences of NHS health services and what it was like to be ill
  - E.g. one girl explained what it was like to have CF, explained her medications and her likes and dislikes. At the end, the girl challenged the doctors and asked them what she had said. It was a very interesting and thought provoking exercise.

# Liverpool

Professor Bernie Carter and Dr Lucy Bray, Edge Hill University

- CHARITY ORGANISATION – Barnardos
  - Disability and inclusion – “Barnardo’s believes that every child, whatever their needs has the right to participate fully in their community and to have the same choices, opportunities and experiences as other children, to make local friends, and to access, play, leisure and recreational facilities” (Barnardo's, 2016b).
    - Provides ‘short breaks’ for disabled children, allowing their families respite and providing new experiences for the children
    - Special Educational Needs Disability Inclusion and Support Service – support, advice and guidance in relation to education, healthcare plan, etc.
  - Advocacy – “Listening to children is at the heart of all Barnardo’s work” (Barnardo's, 2016a). Advocacy includes appreciating and respecting the views of children when decisions are being made for them by local authorities.
  - Advocacy research and resources
    - E.g. Delivery of advocacy services for children and young people aged 0-25 in Wales (Ruscoe, 2011). Using art activities and questionnaires to consult with children, a new advocacy model was developed to improve the experiences of advocacy for children and young people in Wales (see Figure 1). (Ruscoe, 2011)

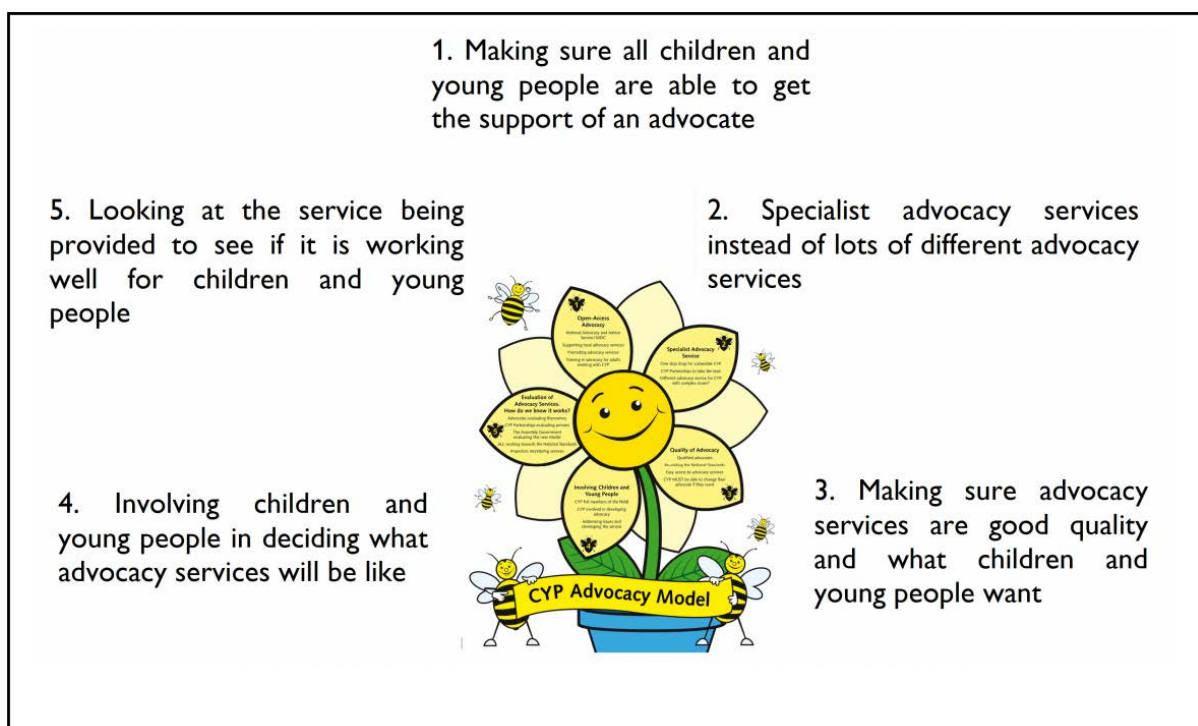


Figure 4: New advocacy model (Ruscoe, 2011)

- STRATEGY – INVOLVE: Supporting public involvement in the NHS, public health and social care research

- [www.invo.org.uk](http://www.invo.org.uk)
- Guided by the Equality Act 2010 (UK), INVOLVE actively seeks involvement from a variety of cultures, experiences and perspectives to advance public involvement in research.
- STRATEGY - &Us, Royal College of Paediatrics and Child Health (RCPCH)
  - <http://www.rcpch.ac.uk/improving-child-health/us-voice-children-young-people-and-families/children-and-young-people/child-0>
  - Children and young people join the RCPCH in improving health services for young patients through their active involvement. This includes,
    - Influencing the training of paediatricians across the UK
    - Raising important issues affecting children and young people's health
    - Influencing key decision makers
    - Participating in research, policy, training, events and communications at RCPCH
- STRATEGY – Investing in Children: Promoting the rights of children and young people
  - [www.investinginchildren.net](http://www.investinginchildren.net)
  - Provides research and participation services by creating appropriate environments and opportunities for children and young people to contribute to service development, and by supporting the adults who provide services to children.
  - For example: Investing in Children facilitated an evaluation of the School Nursing Service in Durham, UK, by seeking the views of young people, parents and education staff. They have also contributed to the development of a guidebook on developing young people's forums.
- STRATEGY – NHS digital badges
  - [www.makewav.es/nhs](http://www.makewav.es/nhs)
  - Makewaves is a community of thousands of schools sharing their creativity and raising achievement with badges. In collaboration with Makewaves and Monkey Well-being, the NHS has come up with their own badges which people, including children and young people, can use to find out more about the NHS and contribute to how it can be improved.
  - It is an initiative to help children and young people gain competency and experience within health services. It is divided into over and under 8 year olds. Children can earn badges when they participate in the different activities/badges provided.



Figure 5: Badges created by NHS (UK National Health Service, n.d.)

- SPEAK “It’s a two-way thing” is an acronym used to assist adults to communicate in a manner that is appropriate for the developmental stage of the child or young person. It is also directed at children and young people, and shows them that they can ask questions when they are unsure of the information that is being provided.  
<https://vimeo.com/108800527>
- RESOURCE – Mosaic approach (Clark & Moss, 2001, 2005)
  - A research methodology used to investigate the daily experiences of young children in early years settings
  - Researchers work as co-investigators alongside children
  - Task based methodological tools such as child-led photography, tours, mapping exercises, and role play (Blaisdell, 2012)
- STRATEGY – Alder Hey Innovation Centre: Participation app
  - App designed to answer questions that parents or children may have about their stay at Alder Hey Children’s Hospital
  - Intended to make hospital visits run more smoothly and improve patient experience
  - Developed by asking previous Alder Hey patients and their parents lots of questions, from where to park and what they like to eat, to what their favourite games are and what they want to know most about clinical procedures
  - “Watson” will then be able to respond to question based on information provided by previous service users
- STRATEGY – Experience-based co-design toolkit
  - Can be used to improve patients’ experience of services.

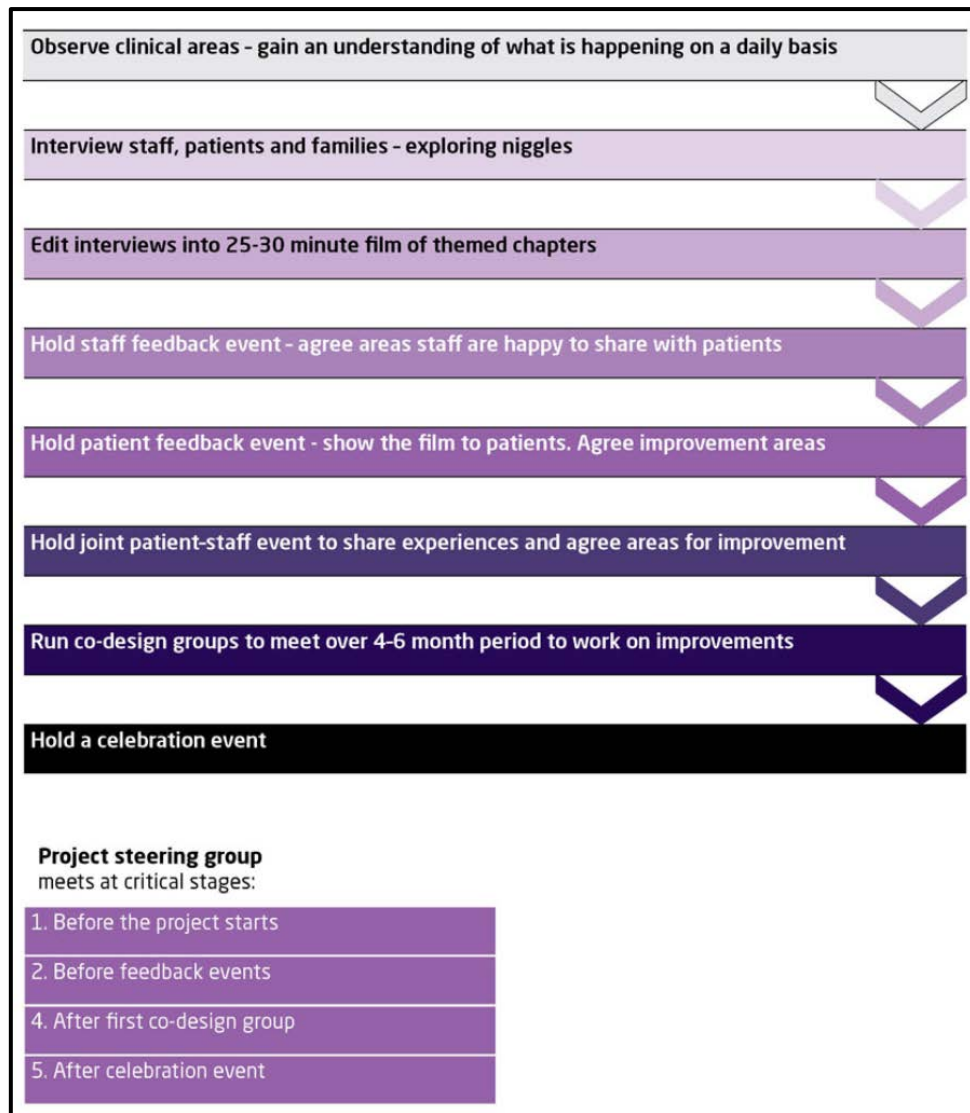


Figure 6: Experience-based co-design (Dale, Stanley, Spencer, & Goodrich, 2013)

- **RESOURCE – Child-centred Nursing: Promoting critical thinking**
  - A book written by a group of academics from the United Kingdom, New Zealand and Australia on issues pertaining to child health nursing, how to promote their participation in society, healthcare and research, their experiences of illness and decision-making and how to apply this knowledge to nursing practice (Carter, Bray, Dickinson, Edwards, & Ford, 2014).

### **Conference: Children and Young People in a Changing World: Action, Agency and Participation, Liverpool Hope University, United Kingdom**

- **IDEAS/PERSPECTIVES - Prof. Jen Qvortrup**
  - Rather than looking at gender, ethnicity and class, there is a gap in knowledge concerning the generational gap between children/adults and childhood/adulthood
  - Gender, ethnicity and class cannot explain the similarities and differences between generations
  - Children's membership in different institution school, family, political and legal

- Family – the epitome of privacy
  - Power, resources and rewards differentiate along dimensions of age
  - Children have more autonomy in Scandinavia versus UK, Germany and France
  - Childhood is constructed out of our notion of adulthood
  - Structural indifference/inconsiderateness – become victims of structure of modern society with reduced resources for children
  - Children are victims of exploitation; referred to as a minority group and subject to paternalism and patriarchy
  - Change in the forum of work – from physical labour to mental work in school yet their ‘work’ in school is not necessarily recognised as such
  - School maintains the ‘generational contract’
  - Minority group – status of exclusion from full participation in society (whether it be by age, culture, religion or number)
  - Age is not mentioned in the preamble of the Human Rights Convention and CRC “Everyone is entitled to all rights and freedoms set forth in the Declaration...”
  - Compulsory education as the differentiator of childhood and adulthood
  - Work (Field to factory to school)
- IDEAS/PERSPECTIVES – Christina Ergler: Pre-schooler’s experiences in and expectation for urban environments
    - Pre-school age range has so far been limited in their ability to inform policy and decision-makers but they have the capability and capacity to make valuable contributions to urban design
    - They should participate in the design and planning of their communities
    - Have opportunities to learn about and care for their environments
    - Mobility and safe and secure environments are very important aspects for them
    - Learning to care and be responsible for their communities
    - Access to the natural environments. E.g. playgrounds and sports grounds
    - Want to be integrated into their communities rather than just child designated spaces
- IDEAS/PERSPECTIVES – Amanda Hatton: Listening to the voices of young people: Developing a model of participative practice
    - Meaningful versus tokenistic participation
    - Model of participative practice based on children and young people’s views (Hatton, 2014)
    - Model is based on three stages: to communicate, listen and respond
    - Relationships are key to enhancing children’s meaningful participation

### **Lindy Simpson, Social Worker and Independent Participation Consultant**

Lindy was previously the Participation and Social Work Lead working specifically with children using mental health inpatient services of a large mental health NHS Trust. She led the development of a unique feedback system which provides the core communication and decision making processes of the Participation Strategy of the service.

- STRATEGY – Participation Strategy
  - Resident young people’s meetings
    - The young people who currently use the service meet weekly
    - Their participation meeting are led by the participation worker and is not open to the clinical team. Information is shared with the young people from



the management and staff team about local events, policy changes, staff changes, therapy provision and other service development issues for them to get involved with as well as day to day residential issues. The young people also initiate ideas. They record the discussion and decisions etc and this is circulated to all staff, management (So they can place items on the management meeting agenda) and a group called The Crew.

- The Crew
  - The Crew has been established for 10 years and consists of young people and parents who have previously used the service. Membership is limited to 2 years so the group continues to evolve. The group have been instrumental in successfully developing the case for a specialist 16/17 year old inpatient ward, as well as changing one unit to become self-catering which included the creation of new Life Skill Worker roles. They have received several national awards and NHS recognition for their work. On receiving the weekly meeting minutes they follow up young people's issues with the management team. They ask the difficult questions on behalf of the resident young people and provide continuity as young people come and go on the ward. Members of The Crew as part of their agreement sign a confidentiality clause and work within the same expectations as members of staff. The members receive expenses and the young people are paid an hourly rate for their time.
- The Management Team
  - meet with The Crew and the Participation Lead is a member of the management team to ensure items are actioned and monitored. This completes cyclical communication enabling progress or reasons why things may not be possible to be shared between resident young people, The Crew and the management team and staff.
  - Current and previous families are included in this process through the monthly Family Support Group. This is open to all extended family members and there is also a notice board which can be viewed by visiting families and all the above parties.
- Evaluation leading to service improvement
  - In addition the participation strategy and plan is informed by an evaluation programme called 'What young people say...'. This is a process that includes individual interviews with each young person at each stage of their care from admission prior to each monthly CPA review, through to discharge. There are two stages to the evaluation the first is to address personal care planning issues immediately in real time to enable effective assessment planning and treatment. This could be something like not having a copy of their care plan or disagreeing with their leave plan or having a query about medication or therapy.
- The second stage is where the data for every interview is anonymised and analysed every 6 months. This identifies themes and trends about the quality of the service from a young person's perspective. These reports go to The Crew and management and staff and young people parents. Priorities for action planning are decided in partnership with young people. The staff really value these reports as they believe they provide a true reflection of the quality of their work. External inspection and accreditation organisations have found these reports provide excellent evidence of the service actively seeking the views of young people and responding through detailed action plans. This programme of work is undertaken by the Participation Team who are clinically trained and experienced but not members of the direct



medical team providing day to day care. It is time consuming work but the outcomes provide detail and direction for effective service improvement

- Six monthly Action Plans for service improvement and development are written/re-evaluated in response to the reports.
- IDEAS/PERSPECTIVES – Lindy Simpson
  - The most significant barriers to children’s meaningful participation are often based upon the values and attitudes held by adults. These values often relate to the adult position of power and the perceived vulnerability or lack of competence of the child. This dynamic affects every aspect of participation in decision making. The impact ranges from respectful age/stage appropriate partnership decision making, to paternalistic beliefs that children could be damaged by involving them in complex decisions. Most challenging are those managers and practitioners who actively marginalise children, with no insight into their own behaviour or the systems and processes they maintain
  - Helping young people in their decision making meetings. Lindy developed the Independent Review Service in a Local Authority for children in care. She developed various tools and information resources with children and young people and led a programme to support young people to chair their own statutory meetings. E.g. *Preparing for a review, the invitation list, the agenda, a seating plan* and the booklet *‘A meeting will go better if everyone has prepared for it’* explaining to children and young people in an appropriate manner what will happen in their MDT meetings, who will be there and what will be discussed (See Appendix C). It includes activities, a checklist and a ‘hints’ page (similar to a FAQ sheet). It also explains to children what their rights are.
- RESOURCE – *It’s your meeting: A guide to help young people get the most from their reviews* (Sinclair & Wheal, 1995)

For further information please contact Lindy at [thinkchairs@hotmail.co.uk](mailto:thinkchairs@hotmail.co.uk)

# Dublin

## Imelda Coyne, Trinity College Dublin

- IDEAS/PERSPECTIVES - Imelda Coyne
  - Under 5's can be involved in shared decision making once they are prepared and information is explained at their level of understanding. Imelda is in the process of writing up the shared decision making model which she has developed and presented at recent EACH conference, New Orleans, USA.
  - Being listened to and being heard - the time, space and opportunity to talk without being rushed is more important for children than actually making a decision.
  - Professionals and some parents are less inclined to share information with 3-5 year olds as they want to protect them from upset and also because they are unsure how much children want to know and how much they want to be involved in decisions.
- RESOURCE - Shared decision making (Imelda Coyne, Amory, Kiernan, & Gibson, 2014)
  - Participatory techniques to aid interviews
    - Wish box (shoe box which children could deposit messages, wishes and comments)
    - Jelly bean game – in response to some questions, children put a jellybean in one of three jars 'none' 'a little' and 'a lot'
    - Decision and people cards representing child, parent and staff – visual depictions of decisions to explore what types of decisions they were involved in and who made the decisions
  - Major (termed big) decisions vs. minor (termed small) decisions
  - Time, opportunity, familiarity with procedures, relationship with nurses, number of admissions, nature of condition (chronic illness) are factors which influence children's involvement in small everyday decisions
  - Some adolescents are acutely aware that 'choices' are not 'real decisions' as their input would not alter the outcome (similar to assent or tokenistic participation). Some expressed frustration with the loss of control in decision-making.
  - For children, involvement meant receiving information, being able to voice their preferences, being listened to, and negotiating how treatments were administered to them.
  - Choice and information sharing are requisite components of shared decision making
- PROJECT - Anna Stalberg
  - A PhD student from Mälardalen University, Sweden has developed an app for children (aged 3 to 5 years) to use before going to the doctor (Imelda to send me the evaluation of this project once it is done).
- PROJECT – Patricia McNeilly, Queens University Belfast, NI
  - PhD graduate who developed a video to explain her study and to obtain informed consent video from disabled children which was innovative and promoted understanding of research purposes.
- PROJECT – Erna Törnqvist (radiographer from Sweden)
  - PhD with 3-9 year olds, preparing them for MRI scan to avoid the use of sedation
- PROJECT – Kiek Tates, University of Rotterdam
  - Looked at turn-taking in the triadic interactions between child, parent and health professional. Focus is on information sharing as the foundation of participation

# Brussels

## Eurochild Conference

- IDEA/PERSPECTIVE – how do we teach children about their rights
  - Where do they find this information?
- IDEA/PERSPECTIVE – Care leavers educating care providers: Could this work for healthcare
  - Vulnerable children (disabled, ethnic minorities, those in alternative care) discussing their experiences of healthcare with policy makers and health professionals and assisting in the development of healthcare professionals paediatric curriculum
- IDEA/PERSPECTIVE – Educating children about their emotions
  - Rather than only educating about the practicalities of life (e.g. maths and money), educating children about their emotions and to respect and cherish each other (e.g. how life would not be what it is without immigration)
- IDEA/PERSPECTIVE – Responsibilities
  - Children have a responsibility to speak up when given the opportunity, NGOs have a responsibility to funnel their voices and decision makers have a responsibility to listen
- IDEA/PERSPECTIVE – Participation in child protection: Essential for sustainable safety for children and families with disabilities. Veronica Smits, Assistant Professor Family and Youth Law, Tilburg University, Netherlands. Maartje Snelders, Child Psychologist, William Schrikker Group, Netherlands
  - To begin the session, we were taken through an interesting activity
    - We each had to blow up a balloon and hold it in front of our faces. The facilitators of the session started to walk around the room with long metal spikes (looked like giant needles) and then asked us to close our eyes. It was so scary when you could hear the facilitator's steps getting closer and closer to where you were sitting. They used this activity to indicate how disabled people can sometimes feel when they have limited information, are in a foreign environment or do not know who or what is around.
  - Information delivery should be based on children's developmental level rather than their age
  - Professionals tend to want to 'fix' things (deficit based thinking rather than strength bases thinking) rather than building on what is already going well
  - A child's network of parents, friends, family, neighbours, etc, need to want to involve us rather than us involving them in family-centred care
  - Model for inclusion – 3 columns: What is going well, what are the difficulties and what needs to happen. During consultations, professionals go through these three questions with parents and children separately to come up with a care plan
- ORGANISATION – SOS Children's Villages: Realising children's rights in alternative care. Kresimir Makvic, Radostina Paneva and Ronan Mangan. Leo M and Arturs Poksans, young persons/presenters.
  - Rights based approach can be used by professionals to challenge historically rooted notions/ideas of children's position in society
  - SOS Children's Village provides training for professionals on how to communicate with children, practicalities of implementing children's rights and how to promote

children's participation in their care. The training is currently focused on professionals working with children in alternative care but it is relatively transferable and could be used by health professionals.

- E-book will be published in the next few months
  - Took us through an excellent activity where we were each given a character. My character was "I moved her with my family. I am close to my parents and my sister is my best friend. Children at school tease me and say I am dirty and an immigrant". A group of 10 of us were all given different characters and placed in a line along one end of the room. One of the members of SOS Children's Village then read out situations such as "a new mechanics class has started for the boys at school" or "some of the kids from school are going to the movies". Each of us had to take a step forward if we felt like we could participate in the activity (based on our characters). For example, my character was a girl and therefore I could not participate in the new mechanics class, and I did not feel like I could join in on going to the movies because I felt like an outcast. By the end of the session, some had stepped all the way to the front of the room and some of us had been left behind, close to where we had started.
- RESOURCES – Advice from the UN
    - Public budgets: How governments should spend money for children's rights. Save the Children resource centre.
    - Children's participation in public decision-making: Why should I involve children? Coordinated by Mafalda Leal, Eurochild. Brussels, 2014.
    - A child-centred investment strategy: Why the investment plan for Europe needs to prioritise children. A working paper. Eurochild, Brussels, 2015.
    - Advocacy toolkit for implementing the EC recommendation *Investing in Children: Breaking the cycle of disadvantage*. Europe 2020 strategy and structural funds. EU Alliance for investing in children. 2014.

# Amsterdam

**Dr Mirjam de Vos-Broerse, Dr Irma Hein, Elske van Spanje, Jeannette Korings, Leonoor Noordermer, Emma Children's Hospital**

- Emma Children's Hospital (166 beds)
  - Wards are separated by age rather than body systems or illness. There are four sections: Teenagers, 1 to 10 year olds, newborns to 1 year olds and the neonatal unit. This method of dividing up the children by age allows for them to be surrounded by age appropriate environments and information. There however a couple exclusions such as the intensive care and oncology departments.
    - For example, the teenagers section has a room specifically designed for them, with a foosball table, a ping-pong table, books, puzzles and board games appropriate for their age range and cooking facilities.
  - The rooms in each ward are divided in half – the left hand side is only for medical equipment and the right hand side is only for 'normal' living purposes. This is so children have an area of 'normality'.
  - The Instruction Room – a room used for discharge planning. In particular, it is where parents and children can go to learn how to conduct procedures that are required at home. For example, nasogastric tube feeding or blood glucose testing. It is a safe environment where they parents and children can practice their skills.
  - Website – Specialised website for children
    - <http://www.emmakids.nl/web/home.htm>
    - It contains videos of children and their experiences, photos and information. For example, 'Who you will meet at the hospital'
    - Whizzie - a doll that explains procedures
- IDEA/PERSPECTIVES - Dr Mirjam de Vos-Broerse
  - Mirjam is a child psychologist who is researching how to involve children in end-of-life decisions. She has developed a training module for paediatricians on how to promote children's' participation in end-of-life decision making.
  - Improving the involvement of parents and children can be achieved by better informing them
  - To promote the participation of children under 5 years old, it is important to listen their parents who can best read their behaviours and symbols
- IDEA/PERSPECTIVES - Dr Irma Hein
  - Important to listen to children –children can be impulsive and not have a good idea of long term consequences, but with this in mind, adults need to guide them and listen
  - 2 to 7 year old discussion group regarding an ear operation where the children were given the opportunity to look at the device
    - They may not have fully understood the process or implications of the operation but at least they were involved
    - It's important to approach them at the correct level
    - Involving children in their own healthcare increases the respect and control they feel over their own health and introduces them to different health experiences
  - When approaching vulnerable children a helpful strategy is to ask older children, who are either currently in a vulnerable situation or have a history of vulnerability, to approach the younger vulnerable children

- This helps to create opportunities for younger vulnerable children to write, draw and discuss option for healthcare service development.
- STRATEGY – Klik: Kwaliteit van Leven In Kaart (Quality of life in clinical practice)
  - <https://www.hetklikt.nu/over.php>
  - Klik ('Click') is a web-based questionnaire which evaluates the quality of life of children who are having or have had treatment from a children's hospital. It is aimed at children 0-18 years who suffer from chronic or life-threatening illness, however parents of children younger than 8 years old are asked to fill out the questionnaire for their child.
  - This project is in response to improving the quality of life of children who suffer from chronic or life threatening illnesses through the early identification of problems/issues, including emotional and social considerations. These issues are then discussed with a health professional in a timely manner and appropriate interventions are offered to teach children how to deal with their illness.
  - The questionnaire asks children how they are doing in their daily life, e.g. at school, home, etc. It then signals orange or red for areas of concern that need to be discussed at their next health consultation.
- STRATEGY – Pedagogisch Medewerker (PM) (similar to New Zealand Play Therapists and USA Child Life Specialists)
  - 15 PMs for the 166 bed Emma Children's Hospital, but they do not work on the neonatal ward
  - Training to become a PM is 4 years long and includes a 10 month internship.
    - There is the option to specialise in children or remain with more broad social education with adults
  - It is protocol for every child (6 months to 13 years old) to be assigned a PM
  - If a child is readmitted then the same PM from previous admissions is assigned to them
  - PMs reduce the need for anaesthetics before MRIs and pre-medications before operations
  - PMs do not do much training with other health professionals although PMs are always available for coaching if required
- IDEA/PERSPECTIVES – Jeannette Korings, Pedagogisch Medewerker
  - Play and visualisation is very important for children <5 years to understand what is going to happen in hospital or during procedures
  - It is important to be interactive. E.g. children <5 years communicate using stories of fantasies, fears and anxieties. <5's are great because of their fantasies.
  - You have to watch what words you use as some have double meanings
  - Humour, fun, play, getting down to their level and trust is imperative
  - PMs can't always be the ones to break the 'bad' news. It has to be balanced with play. However, it is also important for PMs to do their work with nurses, rather than nurses only doing 'bad' things and PMs only doing 'good' things.
  - Palliative care box created by Jeannette
    - This box includes resources to assist PMs in supporting palliative children
    - Some activities included in the box are making a wishing wand, a pot of tears or a secret box, and making pearls out of tears. These activities are used to assist in talking about the positive sides of 'bad' situations.
    - Making memories is another activity that especially helps siblings of palliative children. E.g. Making prints of hands and feet.

- Other resource include emotions cards, a hedgehog puppet ('What can we do to 'unravel' you and help hedgehog open up?'), a mirror ('What do you see in yourself?'), emotion thermometer (scale out of 10), dice to throw and talk about things (e.g. What are you worried about? What can help you? What do you want?).
  - The box also contains a book that is aimed at PMs. It suggests methods such as massage, relaxation oils, breathing exercises and listening to music. It covers topics such as 'What do they know about death, at what age do they know, how do you tell a child and what do you tell them, how might they react at different ages and what strategies to help them talk about their feelings in a playful way'. The book also includes different practices for different religions and what happens to the body after death
  - The box is also aimed at helping parents know what they can do and talk about with their dying child.
- STRATEGY – Infotheek (Acknowledgement: Elske van Spanje)
  - The information at the infotheek is aimed at parents and children (lay people) and anyone can go to the infotheek for medical information or details about the hospital.
  - The infotheek works closely with Pedagogisch Medewerkers and other health professionals to prepare children for their time in hospital and any medical procedures they may encounter.
  - 'Show and tell' suitcases for school
    - When discharged from hospital, children can borrow a 'show and tell' suitcase from the infotheek that contains items relevant to their current/previous illness. It contains anatomic models, books, posters, etc, for the children to 'show and tell' at school. Children teach their peers about their illness and what it was like to be in hospital. 'Show and tell' suitcases are also available for siblings.
  - The infotheek has many resources available to teach children and young people about their bodies, their illnesses, what to expect in the hospital and what to expect after certain medical procedures and treatments. Resources include,
    - Books, puzzles and activities for different ages and illnesses. For example the book *My brother's name is Tis and he is going to die* helps the siblings of palliative children to understand and know what to expect when their brother or sister passes away.
    - Anatomical models of the different parts of the body
    - Lego to build a hospital and all that is in a hospital. E.g. lego nurses, beds and medical equipment.



Figure 7: Infotheek at Emma Children's Hospital Amsterdam

- STRATEGY – Social workers
  - Het Ouderkompas: Compass project for parents and children
    - [www.hetouderkompas.nl](http://www.hetouderkompas.nl)
    - Broken up into different themes, e.g. relationships
  - Op Koers (on course)
    - Online chat groups and focus groups for children.
    - Led by psychologists
    - Aimed at children suffering from chronic or terminal illnesses and their siblings
    - For example, a common discussion is how to deal with looking different from other children at school
  - Social neighbourhood team for vulnerable and minority groups
    - Social workers visit children and their families at home and discuss any difficulties they may encounter.
    - For example, poverty. Social workers help them learn about money, how to spend it or benefits they can apply for from the government. Other common issues include nurturing, education, local culture and dealing with culture shock.
  - Social Wijk Team
    - Uses people within the group to help those who have similar disabilities and/or illnesses.
    - For example, HIV/AIDS group. A person with HIV/AIDS volunteers to explain to health professionals on how to approach them but also volunteers to be a liaison for others with HIV/AIDS



# Conclusion

There are multiple child participation tools and strategies being implemented across Europe and numerous health professionals, social scientists, policy makers, child health advocates and academics, to name a few, who are striving for the better implementation of children's rights, including children's right to participation. In collaboration with some of these professionals, the main purpose of my travel was to identify ideas and strategies that may improve child participation in New Zealand healthcare.

Known barriers to children's participation in healthcare, such as children's position in society relative to adults, can exclude them from important healthcare conversations. Children's level of participation can also be heavily dependent on the timing, quantity and quality of information they receive, including receiving information at a level that is appropriate for their developmental stage. In addition to requiring the support of adults to participate, children do not always know they have the right to be involved in health conversations that concern them, and they may not know how to gather or access health information. For example, how to transform their thoughts into verbal questions or where/who to ask for more information.

A basic definition of health participation is the exchange and negotiation of personal, social and health information and strategies between children, their families and health professionals. However, children may not be able to engage in this process if they do not know how or know that they are 'allowed' to. In conjunction with our existing knowledge of barriers to child participation, greater collaboration with the educational sector is likely to improve the delivery of complex healthcare-related information and skill development necessary for children to participate in health matters that are important to them.

Asking the experts themselves (New Zealand children) about what strategies might promote their participation in healthcare would, in my opinion, be the most beneficial approach to promoting their health and well-being. In developing and implementing participation tools and strategies, greater consultation with New Zealand children themselves is required in the first instance. Children are our most valuable source of information about what strategies might promote their participation in healthcare. This approach is likely to result in efficacious strategies that are grounded in perceptions and experiences of children.

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# References

- Alderson, P. (2007). Competent children? Minors' consent to health care treatment and research. *Social Science and Medicine*, 65(11), 2272-2283.
- Alderson, P., Hawthorne, J., & Killen, M. (2005). The participation rights of premature babies. *International Journal of Children's Rights*, 13, 31-50.
- Als, H. (2016). Program Guide: Newborn Individualized Developmental Care and Assessment Program (NIDCAP). Retrieved June, 30 2016 from <http://nidcap.org/wp-content/uploads/2015/10/Program-Guide-Rev-22Mar2016-Final.pdf>
- Barnardo's. (2016a). Advocacy. Retrieved July 10 2016 from [http://www.barnardos.org.uk/what\\_we\\_do/our\\_work/advocacy.htm](http://www.barnardos.org.uk/what_we_do/our_work/advocacy.htm)
- Barnardo's. (2016b). Disability and inclusion. Retrieved July 10 2016 from [http://www.barnardos.org.uk/what\\_we\\_do/our\\_work/disability.htm](http://www.barnardos.org.uk/what_we_do/our_work/disability.htm)
- Blaisdell, C. (2012). Inclusive or exclusive participation: Paradigmatic tensions in the Mosaic Approach and implications for childhood research. *Childhoods Today*, 6(1).
- Bloom, P. (2012, May 6). The moral life of babies. *New York Times*.
- Carter, B., Bray, L., Dickinson, A., Edwards, M., & Ford, K. (2014). *Child-centred nursing: Promoting critical thinking*. London, United Kingdom: SAGE Publications Ltd.
- Clark, A., & Moss, P. (2001). *Listening to young children: The Mosaic Approach*. London: National Children's Bureau Enterprises Ltd.
- Clark, A., & Moss, P. (2005). *Spaces to play: More listening to young children using the Mosaic Approach*. London: National Children's Bureau Enterprises Ltd.
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*, 18(3), 273-280. doi: 10.1016/j.ejon.2014.01.006
- Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, 20, 2334-2343. doi: 10.1111/j.1365-2702.2010.03582.x
- Dale, C., Stanley, E., Spencer, F., & Goodrich, J. (2013). Experience-based co-design toolkit. Retrieved July 14 2016 from <http://www.kingsfund.org.uk/projects/ebcd/about-ebcd-toolkit>
- Davies, A., & Randall, D. (2015). Perceptions of children's participation in their healthcare: A critical review. *Issues in Comprehensive Pediatric Nursing*, 38(3), 202-221. doi: 10.3109/01460862.2015.1063740
- Dickinson, A., Wrapson, W., & Water, T. (2014). Children's voices in public hospital healthcare delivery: Intention as opposed to practice. *The New Zealand Medical Journal*, 127(1405), 24.
- Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *British Medical Journal open*, 3(1), 1570.
- Great Ormond Street Hospital for Children: NHS Foundation Trust. (n.d.). Hospital children's feedback card. London, United Kingdom: Great Ormond Street Hospital.
- Hatton, A. (2014). Shallow Democracy: In other people's shoes - Listening to the voices of children and young people. In J. Westwood, C. Larkins, D. Moxon, Y. Perry, & N. Thomas (Eds.), *Participation, citizenship and intergenerational relation in children and young people's lives: Children and adults in conversation*. Hampshire, United Kingdom: Palgrave Macmillan.
- Lansdown, G. (2001). *Every child's right to be heard*. London, United Kingdom: UNICEF and Save the Children.
- Ludbrook, R. (2000). Victims of tokenism and hypocrisy: New Zealand's failure to implement the United Nations Convention on the Rights of the Child. In A. B. Smith, M. Gollop, K. Marshall, & K. Nairn (Eds.), *Advocating for children: International perspectives on children's rights* (pp. 109-125). Dunedin, New Zealand: University of Otago Press.

- Me first. (n.d.). Me first: Children and young people centred communication. Retrieved June 20, 2016 from <http://www.mefirst.org.uk/>
- Medforth, N., Timpson, H., Greenop, D., & Lavin, R. (2015). Monkey's health service: An evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about health lifestyles and NHS services. *Issues in Comprehensive Pediatric Nursing*, 38(3), 181-201. doi: 10.3109/01460862.2015.1049385
- Mokey Wellbeing. (2016). Resources. Retrieved June 18 2016 from <https://www.monkeywellbeing.com/resources/>
- Ruscoe, T. (2011). *Delivery of advocacy services for children and young people aged 0-25 in Wales*. Wales, United Kingdom: Barnardo's Cymru Policy and Research Unit.
- Sinclair, R., & Wheal, A. (1995). *It's your meeting: Guide to help young people get the most from their reviews*. London: National Children's Bureau.
- Stern, D. (1977). *The first relationship: Infant and mother*. Glasgow, UK: Fontana.
- UK National Health Service. (n.d.). Badges created by NHS. Retrieved August 8 2016 from <https://www.makewav.es/badges/20302/>
- UNCRC Monitoring Group. (2013). Monitoring the implementation of the United nations Convention of the Rights of the Child in New Zealand: UNCRC Monitoring Group final submission. Retrieved August 20, 2016 from [www.occ.org.nz](http://www.occ.org.nz)
- UNICEF. (2014a). Facat Sheet: The right to participate. Retrieved September 27, 2016 from [http://www.unicef.org/crc/index\\_30228.html](http://www.unicef.org/crc/index_30228.html)
- UNICEF. (2014b). Fact Sheet: A summary of the rights under the Convention on the Rights of the Child. Retrieved September 27, 2016 from [http://www.unicef.org/crc/index\\_30228.html](http://www.unicef.org/crc/index_30228.html)
- Voices, Choices and Law: Weighing children's view in justice proceedings in Liverpool*. (2015, November 5). Paper presented at the Voices, Choices and Law: Weighing children's view in justice proceedings in Liverpool, United Kingdom.