

Children's relationships with professionals

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The Children's Act came into effect in April 2010 and formally introduced children's right to participate in decision-making. This has profound implications for the way that a range of professionals work with children and families. Instead of talking about children and making decisions on their behalf, parents and professionals are now obligated to include children in their conversations. Professionals need to tell children what's going on, inform children about their choices, find out how they feel and what they want, and take these views seriously. For it is only through listening to and considering children's points of view that professionals can grasp the essence of children's experience and act in their best interests.

Children's participation requires a fundamental shift in approach

and practice and poses a number of challenges, particularly for professionals working in under-resourced areas such as the South African health care system.

This essay draws on learnings from three active programmes (see box 1) to consider what is needed to support children's participation as patients in health care decision-making. It focuses on the following questions:

- Why should health professionals involve children in decision-making?
- What does children's participation look like in this context?
- What are the barriers to participation?
- How can we create an enabling environment for children's participation?

Box 1: Active programmes for children's participation in health care decision-making

Phila Impiloⁱ (Live Life) resource materials are developed with young patients and professional medical and nursing staff. The *Phila Impilo* approach strives for a “heart change” in health service providers while sharing information and skills to enable professional and auxiliary personnel to work with children as “partners in health”. Materials are used to supplement existing programmes or are introduced through professional training in a range of public and private health services in South Africa and beyond.

The **Child Nurse Practice Development Initiative**ⁱⁱ works in a range of paediatric settings to enhance nurses' awareness of their practice and how this links to their own values, skills and knowledge; to improve communication between nurses, families and children; and to improve the quality of care. “Work-

ing with Sick Children” is a short course run regularly at the children's hospital and is included as a specialist module in the postgraduate diploma in child nursing at the University of Cape Town. The module enables nurses and students from South Africa and elsewhere in Africa to develop a clear plan to improve practice and shift towards child- and family-centred care.

The **Children's Radio Foundation**ⁱⁱⁱ has helped a group of young patients at the Red Cross Children's Hospital record their experiences and interviews with parents, doctors, nurses and fellow patients, for radio broadcast. While the main goal is children producing radio for children, children's radio programmes are also used with doctors, nurses and hospital management to raise awareness of children's experiences and their capacity to participate in health care decision-making.

Why should health professionals involve children in decision-making?

The Children's Act introduces new provisions for children's consent to medical treatment, surgery, HIV testing and disclosure. For example, children aged 12 and older can consent to their own medical treatment – provided that they are able to understand the benefits, risks, social and other implications of the treatment.¹ The Act also requires health professionals to provide children with health information in child-friendly formats, and to include younger children in decision-making, although they don't have the final say.

Involving children in health care decision-making is not just a legal requirement. It has clear benefits for both children and health professionals. Creating the opportunity for children to talk about their illness and treatment helps alleviate their fears so they can cope better with pain and discomfort. A child who is coached and assisted to make choices about the position they are lying in, or who should be present during medical treatment, has a greater sense of control or mastery during painful procedures.

Consulting with or listening to children enables medical staff to gain important information that would otherwise go unrecog-

nised. For instance, 16 of 18 asthma patients at the Boston Children's Hospital reported using medication in one or more inappropriate ways;² children in KwaZulu-Natal shared how they cannot challenge nurses and caregivers who fail to issue HIV or tuberculosis medication on schedule;³ and young renal patients in Bahrain described their struggle to cope with taking tablets, thirst and stress – issues that health staff had considered to be insignificant⁴.

What does children's participation look like in the health care setting?

Children's participation cannot be compartmentalised as a diagnostic and treatment activity. It should permeate a child's health care environment and experience.

Strong foundations are laid from the start when children and their families are welcomed and supported in the administration process. Health services gain a child-friendly reputation when they are equitable and non-discriminatory. For example, a 14-year-old girl living on the streets who needs treatment for a gunshot wound in the leg is given treatment immediately and not told to come back “clean and with an adult”.⁵

i The *Phila Impilo* project was designed and directed by Jill Kruger through the organisation Young Insights for Planning. YIP strives to improve children's lives by ensuring that their insights and recommendations about issues that affect them in their daily environments are recorded, disseminated and included in official planning processes. Oxfam in South Africa generously supported the development of *Phila Impilo*. See: <http://24.89.112.65/yip.html>.

ii CNPDI is a participatory action-research project based at the Red Cross War Memorial Children's Hospital. See: www.childnursepracticdevelopment.org.za.

iii The CRF gives young people a voice and connects and empowers them to contribute to individual and social change. Through the use of radio and other low-cost technologies, the CRF creates innovative media content made by and for children. See: www.childrensradiofoundation.org/index.php, and the essay on children and the media on pp. 54 – 58.

On admission and throughout their treatment, hospitals and clinics should establish young patients' communication capacity and needs. Each child is affected differently by their health context and circumstances, cultural upbringing, level of cognitive and social development, and physical and emotional state at the time of decision-making. Communication specialists can assist in consultations with sign language, translation, or simply helping children and health professionals understand each other. Supportive tools such as charts, booklets and puppets enable children to clarify medical and physical needs explicitly, to ask questions, get attention or comfort, express emotional states and accept or reject medical procedures.

When children have a clear understanding of their health problem and potential solutions, they can begin to participate effectively in decision-making. This starts with doctors and nurses providing diagnostic and treatment information in ways that children can understand. Children should be able to request more information, raise queries, have time to think about their choices, share their views, and have these taken seriously into consideration. Their compliance to medical procedures alone cannot be construed as choice or assent.

The views of children younger than 12 years old should also be taken into account when decisions are made because young children's ability to understand is present before they develop words to express that understanding. Age is only one of a number of factors that affect a child's capacity to participate (box 2). If it is not possible to comply with the child's wishes, it is important to share what has been decided, why, and how the child's views were addressed in the decision-making process.

Box 2: Understanding children's capacity to participate in consultation

- Children's skills and capacity to communicate are influenced by their maturity, experience, and physical or mental disability.
- Children's desire and capacity to participate in consultation will be affected by various factors, such as self-esteem, fatigue and degree of illness.
- Young children are able to understand what is being said long before they develop words to express that understanding.
- Children often regress (behave like a much younger child) in response to the stress of illness and hospitalisation.
- Children's self-worth and coping capacity are enhanced when they have some degree of control over their own lives and can contribute to their own health and the welfare of others.⁶

Getting consent for treatment from a 12-year-old child is a big task for both clinicians (who are new to this process) and children (who may never have been asked for their opinion before). Children's involvement in decision-making starts with a shift in awareness, and the courage to try. For example, a nurse asks an eight-year-old child confined to bed: "Can I open the window to let air into your room?", or says to a sick newborn: "I can see that sucking your thumb helps a bit with the pain. So let's put this drip on the other hand".

Involving children in decision-making recognises that they have a point of view and honours their preferences in a variety of ways. This includes their relationships, their physical environment as well as their experience of illness or health – how it feels, what it means to them, what they know or remember, who is there, what they hope for, or why they are grieving. Children often remember who was around and how they were spoken to or treated more clearly than an injection they received.

What are the barriers to participation?

The most recent statistics indicate that, in 2006, there were only 1,691 registered paediatric nurses⁷ for a population of 18 million children in South Africa. But a lack of specialised, trained health professionals is only one of the challenges to working in a participatory way with children in the health sector.

Societal and cultural norms and values pose another major challenge since these are inherent in how health professionals and families treat children who are ill (see table 2). The way health services are structured and how they accommodate children and their families can also hinder or facilitate children's participation.

Nurses recognise that nursing care is empathetic care of the whole child, but say that they lack time and skill to dialogue with children effectively. Their heavy schedules and daily distress in coping with many very sick and dying children can stretch them beyond limits and interacting with young patients in an impersonal way helps them to cope.⁸ Despite stressors, most hospital staff members, and especially nurses, are generously caring and committed to the well-being of young patients. Children attest that nurses "love you and do everything for you. They understand if you are lonely and sad" - but they would like clear avenues to report abuse that sometimes happens in hospital settings.⁹

Staff at Clairwood Hospital in KwaZulu-Natal found that consulting with young patients through tried-and-tested children's participation mechanisms reduces daily stressors for children and staff, leads to better and appropriate discipline, and appears to accelerate healing.¹⁰

The *Batho Pele* (People First) principles for service delivery require staff to inform and consult patients about their illness and treatment. Yet medical professionals often build exclusionary

Table 2: Barriers to children's participation

Health workers	<ul style="list-style-type: none"> • Limited knowledge and skills for communicating with children. • Attitude that children should have no role in decision-making. • Limited awareness of children's strengths and weaknesses – what they can do for themselves and where they need help. • Lack of training or access to methods for assessing children's development and capacity to participate. • Insufficient training on how to work with families, especially those in very stressful circumstances. • Inadequate role models in teachers and senior clinicians.
Parents	<ul style="list-style-type: none"> • Pervasive belief in medical practitioners and family/tribal elders as authority figures who “know best”. • Widely prevalent notion that children are inferior to adults, should serve them, and should not be part of decision-making. • Lack of sufficient information and support from health professionals to make difficult health decisions for children. • Failure to inform children about diagnoses, hospital admission and treatment in an attempt to protect them from “bad news”.
Institutions	<ul style="list-style-type: none"> • Staff shortages are often related to inadequate staffing norms that do not recognise the complex care needs of children. • Time pressures. • Inadequate numbers of specialist staff, eg trained paediatric nurses. • Routine rotation of nursing staff which moves nurses who've learnt to work with children to adult wards. • Lack of education, monitoring and evaluation of children's rights and participation.

hierarchies based on “expertise” that shut out nurses, parents and children because the “medic knows best”. This is compounded by the widespread belief that the *Batho Pele* principles do not apply to children.¹¹

Children are excluded from decision-making based on cultural and social beliefs that adults have the knowledge, power and insight to serve children's best interests, and that children should “be seen and not heard”. Nursing staff have acknowledged that:

*Phila Impilo was an eye opener – the hospital did not in the past consult with any child or get any information from children – Batho Pele principles were applied only with adults in the past, but are now also applied with children. Respect for children is key.*¹²

How can we create an enabling environment for children's participation?

Introducing the principles and practice of children's participation through academic and in-service training for all people who work with children is important to ensure that young patients are sufficiently supported to contribute directly to their own health care. Components of education and training include:

Starting with the self

Children are wired to communicate from the moment they are born. So the challenge is not in helping children communicate, but rather in helping adults understand them. Health professionals can be encouraged to recognise how they respond to stress and how they communicate verbally and non-verbally, and consider how this applies to children in their care. They can learn to draw on their own experiences of being a child and in the process start to question taken-for-granted beliefs that children's purpose is to obey and serve adults.

Building trust

Meaningful participation only occurs in the context of a trusting relationship between health care providers, children and their families. Developing a relationship and earning the child's trust also create a foundation of care and respect on which to build (see table 3 on the next page).

Learning to “read” children

Nurses can learn how to “read” children, recognise stress, pain and grieving, and what to expect from children at different ages, starting with newborns. For example, a baby will put a hand over her face when she feels threatened or uncomfortable, so nurses

Table 3: Steps to building relationships of trust

Greet the child	Always greet a child by name. Do not force them to look at you. You need to earn their trust before they will do so. Children who do not look directly at you may be showing respect, as culturally required.
Introduce self by name	Use a form of your name that the child will be able to relate to, for example, Nurse Jane instead of Nurse Raubenheimer. Try to avoid terms (such as “aunty”), because these may imply inappropriate relationships in hospitals. “Aunties” can give you love and care, but some aunties order you about and feel free to punish you in unacceptable ways.
Acknowledge the mother or caregiver	Greet the mother or caregiver by name. A child will take their cue from their caregiver, so if they trust you, the child will warm to you more easily.
Indicate your purpose and how long you’ll be there	Briefly explain your presence – to register the admission, give medicine, or talk about the operation – this helps the caregiver to share in the communication.
Create an opening for the caregiver and child to take the lead	Ask whether they have a preference for someone to interpret, to assist, to help with questions. Try to honour their request or explain why you cannot.
Create a comfort level for communication	Adults seldom realise how they intimidate children when standing over them or sitting behind an official-looking desk.
Reflect your awareness of the child’s condition or activity	Adopt the child’s expression, maybe sad or sore. Express your regret about the soreness. Show interest if the child is engaged in an activity. This could be your entry point for communication.
Ask opening questions about the illness	Some pictures or a doll with similarly located pain, tubes or plasters could help you talk about the illness. Or simply say: “Show me where it’s sore.”
Open communication with the child in a direct and honest way	<p>Tell the caregiver that you would like to ask the child first about their illness or injury. If the caregiver starts to reply, explain that you need to know the story from them too, but must first hear what the child can tell you.</p> <p>Answer children’s questions honestly. If you cannot answer a question, promise to find out... and get back to them! Not doing so will break their trust in you (and often in other health professionals too).</p>
Ask what they think or would like to do about the situation	Children often share information that brings deeper insight than the surface problem identified. A caregiver may convey an option that you have not thought about.
Explain how you will respect their confidentiality	Assure the child and family member(s) that you won’t tell anyone else what you spoke about without their permission. This is essential for building a trusting and respectful relationship.

learn how to read and respond to these signs by repositioning, wrapping and helping babies feel safe.

Building strengths

Health professionals often see their main task as solving the problem or diagnosing the illness. This spills over into how they talk about children on ward rounds and describe the condition in medical terms that neither the child nor caregiver understands. Instead, nurses can be encouraged to focus on the positive. Instead of saying the child “is a *kwashi*” (ie malnourished), nurses can say: “He has shiny eyes and a big smile. His legs are still sore but less swollen”. This communicates health, hope and acceptance. Nursing staff can also tap into children’s ideas about what makes them special through group games and identity activities.

Managing pain and minimising distress

While researchers have found that children can understand the concept of pain and engage in jointly-agreed mechanisms to manage it from the age of four years old,¹³ mothers and other caregivers can often recognise and engage a child around identifying and managing their pain at a much earlier age. Health practitioners should acknowledge children’s pain and distress, and can use non-pharmaceutical methods like reassuring and calming mechanisms (such as repositioning, pacifiers and gentle massage). All these are sustainable and practical within the hospital and home. “Bravery charts” can be used for children from the age of two years old to record, for example, having an injection or blood transfusion (through stars, moons, or other symbols). Instead of encouraging children not to cry, allow parents or caregivers to hold the child, acknowledge their fear, pain and anxiety, and reassure the child by not leaving them to cope alone.

Everyday objects can be used as comforters by sick children.¹⁴ Children aged 5 – 13 years find sock puppets particularly supportive in times of stress. Puppets or dolls may become personal confidantes and play-fellows. Children also need safe havens: Following the introduction of *Phila Impilo*, hospital staff reported that:

*It is now a practice in the wards not to hurt children in their beds so that their bed remains a safe haven in the ward. They are taken away to put in an IV [intravenous] line, for example.*¹⁵

Using tools to support children’s participation

Research shows that children are able to communicate equitably with adults if they are given the choice to select appropriate tools like puppets, dolls and collages. Their repertoire includes words, actions, songs and pictures. Children – who fear adult



Poster design: Discussing different typefaces

anger if they are openly critical or speak in ways that are considered culturally improper – can share information in an indirect and unthreatening way through such tools.

Listening to what children have to say

It is very important that children see action being taken in response to their concerns. For example, following their young patients’ evaluations of the child health service, Clairwood Hospital introduced direct, personal conversations with children in words they could understand. Children appreciated learning about their illness and treatment, their progress and anticipated discharge. Mothers were given extended visiting rights, asked to give children family photos, and to celebrate children’s birthdays. Story time was introduced. Children who were well enough could engage in supervised outdoor play and join a morning prayer song.¹⁶

Young radio reporters at the Red Cross Children’s Hospital chronicled the long wait for a kidney transplant, interviewed a doctor about treatment for a severe burn, and diarised life with a chronic heart and lung condition. Their stories have helped health professionals to shift their focus from the illness to children who are ill. Doctors and nurses continue to be surprised by how children articulate their hopes and fears, their desire to know more about their illness, and their extraordinary resilience in the face of invasive procedures and long stays in hospital.

Recognising the impact of family culture

Health professionals can be helped to see how their own family culture intersects with family responses. Many adults fail to tell children that they are being taken to hospital or what to expect on arrival, and then leave without saying goodbye. They believe that adults don't need to explain their decisions and behaviour to children and that their silence will spare the child the pain of parting and the fear of being left in an unfamiliar location.¹⁷ Change will only happen when there is a commitment throughout the institution to communicate effectively with children, and where systems are put in place to support families and professionals to communicate with children.

Supporting institutional change

Many health professionals still see the mother as the primary source of infection and use this as a reason to exclude parents from wards. However, concerns about hygiene should not come at the expense of the child's emotional safety because the mother's or family's supportive presence is vitally important for a child's health outcome. Even if policy provides for mothers to remain with hospitalised children, most South African hospitals do not cater for this.¹⁸

It is necessary to work across all staff levels when changing attitudes and developing ways to interact with children and families. A critical first step is for each health team to commit explicitly to the practice of participatory consultation with children, to devise a strategy for action, processes for implementation, and a management plan that dovetails with institutional frameworks.

Conclusion

Experience from hospitals around South Africa indicates that children's participation is personally affirming for all involved. Outcomes are most effective when members of professional teams grasp the essentials and develop a process that is customised for their particular service and internalised in all levels of service delivery through standard norms and procedures.

When children's participation is an integral component of service provision it eases staff workloads rather than increasing them. By ensuring, in so far as possible, that children and their families play a key part in decisions about health treatment and care, sound decisions are possible within the health sector. In practice, effective children's participation is found to improve the prognosis for successful treatment, to decrease hospital-caused errors and to heighten patient and family satisfaction with health care.¹⁹

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