# CHILDREN AND COVID-19 ADVOCACY BRIEF

# Towards child-centred COVID-19 care



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The COVID-19 pandemic has had a direct and profound affect on children, even though they are less likely to spread the virus and are at lower risk of infection and serious complications than adults. Yet the primary focus on adult COVID-19 care has meant that children's specific needs were not adequately recognised, planned for or addressed in the health care system. This became increasingly evident as the health system became strained under the volume of adult infections, hospitalisations and deaths.

This advocacy brief draws on the experience of the Western Cape, one of the early epicentres of the pandemic in South Africa, to reflect on the extent to which children's needs were addressed across the COVID-19 care continuum. It identifies opportunities to enhance the care of children infected or directly affected by COVID-19. It should be read in conjunction with the complementary brief on the disruption of routine health care services.

# How did the health system consider children in its initial response to the pandemic?

Childhood is a precious time in which children's optimal development is critical for allowing them to attain their capabilities. The window of opportunity to address their health care needs and development is narrow and cannot be postponed as any delays may have long-lasting effects.

As the SARS-CoV-2 pandemic (COVID-19) spread across the globe, children appeared to be less likely than adults to contract or become seriously ill with the virus. Children were also thought to be less likely to spread the virus. Whether this was due to some existing immunity to common childhood coronaviruses, or some other unique viral- or agerelated trait, was not clear.

From the outset, the health sector focused on preventing and containing the spread of the virus and managing those at risk of severe COVID-19 disease – mostly adults. This meant the complex needs of children were not anticipated in initial plans to prevent community and hospital spread of the virus and to care for those exposed or infected with COVID-19. The rapid flow of new information which followed the global effort to understand the pandemic also led to much uncertainty about the best ways to diagnose, treat and contain COVID-19 infections in children, leading to significant delays in the development of paediatric clinical guidelines.

The first COVID-19 management guideline developed by the National Institute for Communicable Diseases and the

National Department of Health was released in February 2020, with an update in March 2020. Yet neither of these documents contained any reference at all to children. At that stage, epidemiological knowledge of COVID-19 was limited and even more so in children. The initial 'person-under-investigation' definitions specifically excluded children because the symptoms of children with common respiratory illnesses overlapped with the case definition for COVID-19. This left paediatricians uncertain how to detect children in need of specific health services.

Well-resourced provinces such as Gauteng, Kwazulu-Natal and the Western Cape developed their own paediatric guidelines towards the end of March/April 2020. These helped inform the development of national guidelines in order to provide all provinces with direction and assistance on how best to manage children.<sup>1</sup>

However, the national guidelines on managing children took a relatively long time to develop and changed frequently in response to new findings. The exception was the guidelines for maternal and neonatal care,<sup>2</sup> which were distributed to all birthing units in the country by 15 April 2020. However, guidelines for infants and older children only emerged towards the middle of May 2020, and the outputs were not systematically disseminated across the country.

### What was the extent of child COVID-19 in the Western Cape?

In the Western Cape, approximately 12 300 children were documented to have contracted COVID-19 between March 2020 and March 2021,<sup>3</sup> accounting for only 4% of all laboratory cases confirmed in this province.

Figure 1: COVID-19 cases in children under 18 years, Western Cape, March 2020 – March 2021



Source: Western Cape Provincial Data Centre

Mortality was mercifully low, with only 59 child deaths reported in the first year. Most deaths occurred in young children and in older adolescents, as illustrated in Figure 2. Older children and adolescents were far more likely to suffer from co-morbidities, with these being present in 55% and 62% of children aged 10-14 and 15-17 respectively, compared to only 12% in the younger children. (see Table 1) Neonates were not tracked separately resulting in a lack of clarity about their COVID-19 trajectory.

#### Table 1: COVID-19 deaths and co-morbidities in children, Western Cape, March 2020 – March 2021

Age	Number of deaths	Number with comorbidities
under 1	18	1
1-4	10	1
5-9	5	2
10-14	9	5
15-17	17	10

Source: Western Cape Provincial Data Centre

Figure 2: COVID-19 deaths children under 18 years, Western Cape, March 2020 – March 2021



Hospital admissions were far higher in younger children, and the age 0-4 category constituted just over 50% of all admissions (Table 1), of whom 1 in 5 had a comorbidity.

Neonates were not tracked specifically, as few were symptomatic, and none died of COVID-19. For example, at one of the largest maternity hospitals, only 5 newborns were tested in the first 3 months and no tests were done after that, due to the negligible infection rates and clinical impact on newborns.

Some of the hospitalisations related to an unusual COVID-19 complication in children, known as MIS-C as outlined in Box 1.

#### Table 2: COVID-19 hospital admissions, Western Cape, March 2020 – March 2021

Age	Number of children hospitalised	Number with comorbidities
under 1	445	64
0-4	466	118
5-9	252	56
10-14	240	62
15-17	323	86

Source: Western Cape Provincial Data Centre

#### Case 1: MIS-C: an unusual child complication of COVID-19

One of the unusual complications in children, noted during the first wave of infections in Italy and the United Kingdom, is MIS-C (Multisystem Inflammatory Syndrome in Children), where different body parts can become inflamed. This is a childhood rheumatic disease similar to Kawasaki Disease (a condition that causes inflammation in the walls of some blood vessels in the body). MIS-C children are generally more ill as it involves the heart muscle, gastro-intestinal tract, brain and kidneys. Global and national health agencies have launched numerous projects to try to understand this "new" condition and how best to diagnose, treat and manage children. Children who acquire MIS-C frequently require intensive care and expensive tests to confirm the diagnosis. Whilst the diagnosis and clinical features of MIS-C have since become clearer, managing children in low-and-middle income countries is difficult as other infectious diseases may mimic MIS-C and expensive diagnostic tests and treatments are limited and ofttimes unavailable, and illustrates how the pandemic exposes global inequities.

Red Cross Children's Hospital and the Paediatric Department of Tygerberg Hospital saw about 70 children with MIS-C in the first 10 months of the pandemic, of whom approximately 40% required ICU admission.

### To what extent did the health system provide child-centred COVID-19 care?

Children were initially overlooked in the health system response to the pandemic. Whilst laudable efforts have been made to correct this, more needs to be done to ensure better care for children going forward – at every stage of the patient journey from prevention, through to contact tracing, quarantine and isolation, and hospital admission – and looking beyond treatment to consider children's needs for rehabilitative or palliative care.

#### Child-centred communication

Communication has played a key role in informing communities about the pandemic, and what measures they can take to protect themselves from COVID-19 infection and access support during various stages of lockdown. However, much of the communication in the mass media has been adult focused. There is therefore an urgent need to develop child-centred materials and channels to communicate with children to address their questions, fears and concerns.

"Coronavirus sometimes make me scared cause sometimes I can cough or have heavy breathing and I'm not sure if it is Coronavirus or just my Asthma. And if something like that has to happen to me it would affect my chest even more because it will give me heavy breathing. And sometimes when I get to, uhm, frightened, then my chest sometimes turns tight and then it could affect my chest even more."

> Uzaamah (13 years old), RX Radio reporter, March 2020.

"Some say this virus doesn't exist. I'm trying my best to make sure that people stay safe. But sometimes I feel like I'm not trying hard enough because some people say don't follow the rules. Meanwhile, I try to tell them to. I'm suffering a lot with my schoolwork because I no longer go to school every day. I go only three days a week and it is hard to study at home because there's a lot of noise."

Rethabile (15 years old), RX Radio correspondent, October 2020.

Children need to be assured that they are not alone; they need to see how others are experiencing the same problems they are and how they are dealing with them; and they need guidance and support on how best to change behaviour to protect themselves and others. Behaviour change is a critical part of the fight against COVID-19. Developing materials in consultation with children and bringing their voices to the fore is incredibly powerful in educating and informing their peers and families.

Providing safe platforms for children to talk about their experiences, challenges and concerns around the pandemic is also critical. This includes the work of RX Radio, a children's radio station led by children and situated in the Red Cross War Memorial Children's Hospital,<sup>4</sup> and the Western Cape Children's Commissioner's ongoing dialogues with children and families<sup>5</sup>.

#### Case and contact tracing

Another important part of the COVID-19 response was the establishment of outbreak response teams. These teams traced the contacts of individuals with laboratory-confirmed COVID-19 and advised them on how to safely manage themselves and those they lived with.

None of the initial guidelines and information sheets included any questions or information about children. This meant that contact tracers did not ask if there were any children in the households, nor were they provided with any information on how to keep children safe or manage them.

In response to this gap, a member of the contact tracing team developed a set of guidelines to encourage the team to purposively ask about children in the household.<sup>6</sup> Key guidance included:

- Not separating young children from their COVID-19 positive mothers/caregivers, unless they were too ill to care for their children
- Continuing breastfeeding, unless the mother was too ill, and
- Supporting children psychosocially by teaching them how to keep safe and allaying their fears

Adults were also advised how to identify the signs and symptoms of COVID-19 in young children; manage mild illness; maintain child nutrition; and keep children active during lockdown. Resources on how to keep older children active and promote learning were also passed on, and where needed, children and their caregivers were referred for psychosocial support.

#### Quarantine and isolation facilities

If the home-setting was not conducive for isolation or quarantine, then contacts were advised to enter one of the isolation and/or quarantine facilities set up during the first wave of the pandemic. And this was the case for many families living in small, overcrowded spaces, as outlined in Case 2.

Based on the experience in the Metro district, isolation facilities were not set up with children in mind. For example, whilst wholesome meals were provided to adults and older children, meals for infants were not considered. Mothers with young children were allowed to take their children with them to the isolation facility, provided they were well enough to care for them. Yet children 12 years and over who were on their own were allocated to a room and had minimal support and supervision, as staff capacity was limited. Where children had to guarantine due to a seriously ill or hospitalized parent, these facilities could not accommodate them if they were younger than 12, due to a lack of childcare. Despite numerous advocacy efforts to appoint a pool of child-carers for such instances, this did not materialize. Placing children in a residential care facility was also problematic due to risk of exposure to other children, and many difficulties arose with testing large numbers of children before placement. Social workers were reluctant to place children before they were tested, and testing facilities were reluctant to accommodate large numbers of children for testing. An instance involving seven children with a gravely ill mother and largely absent father required intense and lengthy negotiations with Red Cross Children's Hospital colleagues to get them tested before being placed in safe care.

In the Metro district, quarantine and isolation facilities were generally underutilized during the first wave, and these were therefore reduced to only one quarantine and two isolation facilities during the second wave, with no prospects of accommodating children.

#### Obstetric and neonatal care

Whilst direct infection with COVID-19 was not of concern in newborns, the circumstances of their birth and subsequent care if they needed hospitalisation were significantly affected due to fears that parents will introduce and spread COVID-19 during their hospital visits and stay.

#### Case 2: Supporting families affected by COVID-19 infection and isolation

A young single mother with four children, aged two to 12, contracted COVID-19 and entered an isolation facility (together with her four-year-old who also tested positive) due to fears for her other children who were left in the care of her elderly mom and her grandfather.

None of the other family members knew their COVID-19 status and advising them on how to quarantine in their two-roomed shack was tough. Care for the two-year old raised uncertainty, as the grandfather normally assisted and they feared for his health. The mother's matriculant brother found it tough to quarantine at home, as he was concerned about his schooling.

Supporting the family involved phoning the mom in the isolation facility and then daily calls to the grandmother,

who had to be contacted via a neighbour, as she did not have a phone. Advice was also given to the neighbour on how to keep safe.

Part of the support involved taking goods for the little boy in the isolation facility, arranging food parcels for the family, sending money to purchase electricity, counselling the matriculant about isolating and keeping up with his schoolwork, and managing the fears of the family and neighbours with whom they shared toilets.

While in isolation, the mom lost her job, meaning the family had no income, except for child support grants for only two of the children and old age pensions for the elderly.

These dilemmas created a tension between the need to protect mothers, infants and health workers from COVID-19, and the benefits offered by breastfeeding and family care.

Eventually the following guidelines were put in place:

- Partners were no longer allowed to be present during labour and childbirth unless adequate social distancing could be put in place
- Mothers were allowed to visit, care for, and breastfeed their ill neonates, and
- Mothers and caregivers were able to visit and room-in with their young children.

A week after the first case of COVID-19 was detected, the South African Human Milk Bank Association circulated a clear recommendation backed by global bodies UNICEF, the World Health Organization<sup>7</sup> and the Centers for Disease Control and Prevention, that breastfeeding was safe<sup>8</sup> and women were encouraged to continue breastfeeding while limiting transmission by wearing a face mask.

Case 3 presents an example of measures put in in place in a hospital to protect neonates, mothers and staff.

#### Hospitalisation of children with COVID-19

As screening protocols for COVID-19 became more widespread, a greater number of children were identified as infected, whether this was the primary reason for admission or not. These children ideally required isolation to curb the spread of infections.

Parental visiting rights were initially limited to minimize risk of spreading infection. This led to tension between the rights of children to be in a safe environment and their rights not to be separated from their caregivers. At the same time, the safety of health workers and other hospital staff, who were at great risk of COVID-19 infection, had to be considered.

Hospitals had different approaches to this dilemma. At the Red Cross Children's Hospital, the risk of increased stress and poorer care for children if they were isolated was judged to outweigh the risk of spreading COVID-19. Sophisticated cohorting and testing procedures were put in place. Whilst these had a profound impact on hospital flows, it allowed for each child to at least have one caretaker admitted with them.

#### Case 3: Ensuring the optimal care of mothers and newborns

Mowbray Maternity Hospital is a large dedicated maternal and neonatal hospital delivering 1 000 babies/ month. With this large throughput, it was essential to decrease non-patient flow and rapidly get evidenced-based guidelines and standard operating procedures in place to manage the pandemic. Available research indicated that transmission to newborns was very rare<sup>9</sup> and the focus shifted from the neonate to preventing infection of staff and mothers in the nursery. To limit spread, the following measures were instituted:

#### General prevention measures

- Involvement of infection control from the start of the pandemic to ensure a safe environment was maintained in accordance with global recommendations.
- Campaign for universal masking of all staff and mothers (prior to the national call for this) with N95 masks reserved for aerolisation procedures
- Screening of all staff and visitors to neonatal unit

#### Promoting breastfeeding

- COVID mothers were encouraged to breastfeed and wear a mask to prevent transmission
- Donated breastmilk supplied for the most vulnerable newborns

• Where space was limited or the mother was positive or in quarantine, special permission granted for family to drop off breastmilk during lockdown

#### Avoiding separation of mothers and babies

- Mothers and infants kept together if the mother was well and COVID-19 positive and baby was term and well
- Rooming-in facilities open for breastfeeding mothers (lodger moms)
- Social distancing in Kangaroo Mother Care wards, by halving the beds/ room but keeping overall total capacity
- Mothers had 24/7 access to newborns, but fathers and extended families were only allowed in exceptional cases such as severely ill or dying neonates. Video calls by mothers to family members were allowed.

#### Managing exposed and positive babies

- Development of evidence-based standard operating procedures and guidelines to manage COVID-19 exposed and positive neonates were developed in conjunction with colleagues provincially
- Managing all neonates in closed incubators

#### COVID-19 care of adolescents

In waves 1 and 2 of the pandemic, most adolescents with COVID-19 symptoms and disease had only a mild disease and were treated at home. But as the delta variant becomes more prevalent, there are more adolescents acquiring the disease, becoming symptomatic, and requiring hospitalization.

Adolescents occupy an awkward space in the health care system where they are too old to be accommodated in paediatric facilities and their needs are often not adequately considered on adult wards.

This means that most adolescents with COVID-19 enter adult wards, where they are exposed to very sick and dying adult patients, without their caregivers present. Yet all children, including adolescents, are entitled to family care and support. Health professionals should therefore consider admitting younger adolescents with COVID-19 to paediatric wards, cohorting older adolescents, and finding ways to enable all these children to stay in regular/daily contact with their families.

Isolation and quarantine also place a heavier burden on adolescents, and they need additional support to stay away from their peers during this highly social stage of development. Adolescents are also under pressure to keep up with their schoolwork, and for those in their matric year, being ill and missing school adds to their stress, making psychosocial support to this age group all the more important.

#### Care of children with other health conditions

COVID-19 also severely disrupted hospital services for the majority of children who did not have COVID-19. At any

given point, only 17-20 children in the 282-bed Red Cross Children's Hospital were either confirmed COVID-19 cases or a 'person under investigation' for the infection. Yet, even in this dedicated children's hospital, services for children without COVID-19 were affected due to increased staff stress, workload and task-shifting in response to the pandemic (see the routine health services brief).

Adapting clinical services at the Red Cross Children's Hospital involved rapidly de-escalating elective procedures such as surgery, imaging and investigations. Following an informal rapid assessment, surgical procedures deemed to be urgent were allowed to go ahead, while less urgent procedures were postposed. All non-urgent outpatient appointments were rescheduled. This was done by developing guidelines to manage the outpatient services differently using telephone triaging to manage patients remotely, and early de-escalation to give staff time to plan and prepare for the first wave. As a result, crowding was eliminated in clinical areas and the pharmacy. As predicted, the de-escalation has led to significant backlogs in many services and delayed admissions of children with chronic illnesses who have not been able to access health facilities easily. Other hospitals adopted different approaches to address similar challenges.

#### Palliative and rehabilitative care

Children who were hospitalized during the pandemic, either for COVID-19 or other illnesses, have endured periods of fear, uncertainty and separation from their loved ones. And many more children have experienced the unprecedented loss of loved ones (grandparents or parents), of livelihoods as their parents face unemployment, of friends and of routines as schools and early childhood development facilities closed.

#### Case 4: Strengthening social work services to respond to complex care needs

The fear, uncertainty and economic hardship triggered by the pandemic also increased the demand for social work services. Funding from the Michael and Susan Dell Foundation enabled Red Cross Children's War Memorial Hospital to appoint two additional social workers to provide counselling and support to children and families both directly and indirectly affected by COVID-19.

For in-patient cases, the social workers called the parent or caregiver every day to provide support and assistance as needed. Parents of children diagnosed with COVID-19 expressed high levels of anxiety and, wherever possible, parents were linked to the medical team so that the doctors could answer their questions about their child's condition and medical treatment.

The social workers also extended support to the

families of outpatients through an initial assessment and follow up call, and families could then send an SMS or WhatsApp message if they needed the social worker to contact them. The social workers helped families address concerns around children's care, safety, mental health and school attendance; and negotiate more challenging issues such as unemployment, violence against women and children, loss and bereavement.

Thanks to the support of donors and the general public, the hospital was also able to provide children and families with material support – including colouring-in books, toys, clothes and blankets for children in hospital, care packs for parents at the bedside, and food parcels and transport money to enable children to return home and access treatment, follow-up care or a place of safety. This requires careful management and support of grief and loss as well as practical support (as outlined in case 4).

Nearly 52 000 adults were hospitalized and 12 000 died of COVID-19 in the Western Cape during the first year of the pandemic,<sup>3</sup> many of them leaving behind children and grandchildren in need of care and support to cope with fear, anxiety and bereavement. PatchSA, a children's palliative care network, has developed an online course to respond to this growing need and to help families, teachers and health workers support grieving children in the time of COVID-19.<sup>10</sup>

Whilst relatively small numbers of children died so far, for the 59 children who died, having had palliative care support available to them, their siblings, their school friends and families should be considered a necessity rather than a luxury – and support mechanisms to allay the fears and anxieties of the 12 300 children who contracted COVID-19 is also crucial. Whilst various individuals and organisations stepped in to provide psychosocial support as best as possible, these efforts were not co-ordinated or widely available.

In addition, there is growing concern around long-COVID in children.<sup>11</sup> Where either symptomatic, or asymptomatic COVID-19 continues to have long-term effects on children with symptoms such as 'fatigue, muscle and joint pain, headache, insomnia, respiratory problems and heart palpitations'. While research on long-COVID in children is still limited, concerns have been raised about how long-COVID may affect children's ability to continue and cope with schooling. Practitioners and those caring for children therefore need to be aware of the possibility, look out for ongoing symptoms in children, and ensure they have access to ongoing treatment and rehabilitative services.

# Care and protection of children whose caregivers are hospitalised or die of COVID-19

The needs of children should also be considered when providing adult COVID care. We know that the infection, quarantine, hospital admission, recovery or death of adult parents or caregivers has a profound impact on the care and protection of their children. Yet, to date, routine questions about children have not been incorporated into the adult clinical guidelines, algorithms or stationery. In addition, systems need to be put in place to enable children to maintain contact, be kept informed about the treatment and prognosis of parents and caregivers, and to ensure they are adequately supported at a time of fear and uncertainty.

## What are the lessons learned and key recommendations?

Children are especially vulnerable during periods of upheaval such as the COVID-19 pandemic. Their healthcare, development and quality of life are time-sensitive and depend on well-functioning services. Children's needs cannot simply be placed on hold while other priorities are addressed.

Systems that care for children should work to proactively identify opportunities to support the ongoing healthcare and development of children despite other pressing needs. The focus on a life course approach that enables South Africa's children to thrive cannot be abandoned and should ideally be bolstered in the delivery of routine and specialised services during periods of crisis such as COVID-19.

Section 28 of the Constitution gives special rights to children, and the "best interests of the child" should guide every facet of the health system's response to children infected and directly affected by COVID-19 across the care continuum. It is therefore important to put measures in place to:

 Provide safe platforms for children to talk about their experiences and concerns; and access to child-friendly information to help alleviate their fears and help them avoid infection.

- Ensure that systems are put in place to identify children in need of care and protection during contact tracing and when adults are admitted to hospital with COVID-19.
- 3. Ensure children with COVID-19 are accompanied by a primary caregiver as their support in hospital helps alleviate stress and aids physical recovery.
- Do not separate infants and young children from their COVID-19 positive mothers/caregivers (unless they are too ill to care for their children) and promote breastfeeding.
- 5. Advocate for affordable medicines and diagnostic tests for children.
- Protect resources and essential non-COVID-19 care for children to avoid backlogs, respond to the surge season, and avoid the permanent loss of paediatric beds.
- 7. Ensure that there are representatives for child health on national and provincial command structures who are supported by a clinical governance team to ensure that services for children are purposively planned for in future waves of the pandemic and similar disasters.

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This is one of a series of advocacy briefs that trace the impact of COVID-19 on children in order to identify opportunities to better support children during the COVID-19 pandemic and similar crises.

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