



ONE CHILD
ONE FAMILY



Inclusion and participation make the difference in children's care; Youth Accountability and Disability Inclusion in South Africa (YADIS)

2021 Submission to the UN Convention on the Rights of the Child Day of General Discussion: Children's Rights and Alternative Care

The University of Leeds, University of Pretoria, Hope and Homes for Children, Bishop Simeon Trust, One Child One Family HHCSA, and DeafKidz International are joining forces in a unique partnership to support youth accountability and inclusion in South Africa. The Youth Accountability and Deaf Inclusion in South Africa (YADIS) project is developing an inclusive youth leadership programme for vulnerable children in Ekurhuleni, Gauteng Province, South Africa so that they may claim a greater voice within their communities in order to guide and support service delivery through accountability. YADIS will combine community development, arts-based leadership and participatory filmmaking, inclusive communication, knowledge exchange and advocacy for youth accountability and inclusion, with a focus on ensuring the inclusion of deaf children in a partnership that positively fosters the integration of deaf and hearing.

Institutions do not meet the best interests of the child and care systems around the world must be reformed. To ensure quality for all children, child care and protection systems must put children at the centre. The transition from institutions to family and community based care must be designed with children and for children, must respond with a suitable solution to meet the needs and circumstances of each individual child, and must leave no child behind. Youth accountability and disability inclusion are critical elements that run through a well functioning child care and protection system and lead to the best outcomes for children. States must enable and support all children to participate in care reform, shape the decisions about their individual care, and inform practice so that no child is left behind and all children are supported to grow and thrive in safe and sustainable families.

Disability inclusion, participation and inclusion are roadblocks to care reform

Children with disabilities are overrepresented in institutions. 1 in 3 children in institutions have disabilities - compared with 1 in 6 of the world's population¹². In some countries it is much higher³. Children with disabilities are exposed to significant violence within institutions.⁴ They are at

¹ United Nations, General Assembly, 'Global Study on Children Deprived of Liberty', A/74/136. 2019.

² World Health Organization, 'World Report on Disability'. 2011.

³ Pact, 'Information on DI reform'. 2021. <http://reform.diplatform.org.ug/>

⁴ Pinheiro, P.S., 'World Report on Violence against Children.' United Nations Secretary General's Study on Violence against Children, (2006), 9/27, 16/53/57/58/59.

heightened risk of violence, physical, emotional and sexual abuse and exploitation⁵⁶. Driven by stigma and discrimination, children with disabilities are excluded from families and communities⁷ - being more likely to experience physical and sexual violence and neglect than their peers⁸ and at increased risk of gender-based violence⁹. The lack of robust, reliable and comparable national data on children with disabilities poses a challenge to the delivery of inclusive programmes and services¹⁰.

It is particularly important that children in care, at risk of separation from their family, and children with disabilities are supported to guide, influence and hold institutions accountable, as these children are fully reliant on the application of policy for life opportunities (for example, care placement, schooling and healthcare). However, children are rarely consulted or included in decision making and adult-led considerations of the 'best interests of the child' prevail. Children with disabilities are further excluded, including through legal restrictions, from decision-making in matters regarding the child themselves¹¹.

Case management processes afford ample opportunity to directly engage children in their care decisions and placements, for example through assessments, informal visits, formal decisions and reviews yet this is rarely adhered to in practice. Engagement and intervention are provided by professionals who have identified both the need and the solution, with no engagement with children themselves¹². Lack of inclusion is related to perceptions that children and young people are not capable of contributing, lack of resources and structures to support such contributions, and lack of

⁵ United Nations General Assembly. 'Global Study on Children Deprived of Liberty', A/74/136. 11 July 2019

⁶ Pinheiro, P.S., 'World Report on Violence against Children.' United Nations Secretary General's Study on Violence against Children, (2006), 9/27, 16/53/57/58/59

⁷ United Nations General Assembly 'Status of the Convention on the Rights of the Child' A/73/272. 30 July 2018

⁸ Jones , L. et al. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies, *The Lancet*, vol. 380, no. 9845; and Deutsche Gesellschaft für Internationale Zusammenarbeit, "Inclusive education and forced displacement: avoiding lost generations — providing equal access to quality education and safe learning environments", Science to Policy Brief, 2016.

⁹ UN Committee on the Rights of Persons with Disabilities. 'General comment No. 3 (2016) on women and girls with disabilities.' CRPD/C/GC/3. 25 November 2016.

¹⁰ United Nations General Assembly 'Status of the Convention on the Rights of the Child' A/73/272. . 30 July 2018

¹¹ Lansdown, G., Berman Bieler, R. and Mitra, G. 2013. TAKE US SERIOUSLY! Engaging Children with Disabilities in Decisions Affecting their Lives.

¹² Rudolph, N., Millei, Z., & Alasuutari, M. Corrigendum: Data practices and inequality in south african early childhood development policy: Technocratic management versus social transformation. *South African Journal of Childhood Education*. 2019. 9(1).

willingness on the part of decision makers to take on board children's feedback in order to achieve improved outcomes¹³. For children with disabilities, these issues are compounded by factors such as persistent negative attitudes, communication barriers, lack of accessible and appropriate information¹⁴ thus further excluding them from decisions about their care.

Domestically, South Africa has an exceptional legislative and policy framework aimed at the deinstitutionalisation of all children, with children with disabilities being a core tenet of reforms. § 28 of the Constitution¹⁵, the Children's Act No 38 of 2005¹⁶ and allied policy frameworks, National Disability Policy¹⁷ (NDP) and subsequent White Paper on the Rights of Persons With Disabilities¹⁸ (WPRPD), confirm and reaffirm the need to have the child at the centre of the decision making process and that institutions for children are a last resort.

However, this policy commitment to inclusion and participation is not adhered to in the majority of cases - especially for children without parental care, children who are in the care system, children with disabilities and children with disabilities who are in care. The prevailing attitudes of professional social workers favours a top-down approach, where decisions are made on behalf of the child by a multi-sectoral panel of professionals. Inability to access sign language interpretation, or have specialised training leading to a fear of inadequacy leads to avoidance, meaning deaf children are not included in decision making. Implementation of the WPRDP is hardly evident in the lives of families, children and young people living with disability in communities. The absence of adequate socio-economic service delivery and the de facto exclusion of children and young persons with disability from the majority of state, NGO and CBO-led programming, means that many are committed to institutions and 'special schools' with a residential component, in an attempt by

¹³ Kay, E., & Tisdall, M. Conceptualising children and young people's participation: Examining vulnerability, social accountability and co-production. *International Journal of Human Rights*, 21(1), 59-75. 2017.

¹⁴ ¹⁴ Lansdown, G., Berman Bieler, R. and Mitra, G. 2013. TAKE US SERIOUSLY! Engaging Children with Disabilities in Decisions Affecting their Lives. UNICEF. 2013.

¹⁵ Government of the Republic of South Africa. Constitution of the Republic of South Africa, Act 108 of 1996.

¹⁶ Government of the Republic of South Africa. Children's Act No 38 of 2005.

¹⁷ Government of the Republic of South Africa. National Disability Policy. 2015.

¹⁸ Government of the Republic of South Africa. Department of Social Development. White paper on the Rights of Persons With Disabilities. 2016.

under-supported parents and carers to access necessary developmental and support services. Child participation is at best tokenistic.

In a report by Hope and Homes for Children South Africa, 'One Child One Family' identified a key gap in the child protection system during the second phase of its pilot demonstration project for deinstitutionalisation and care system reform in Gauteng Province. Many of the reunifications of children living in institutions into their biological family were complicated by resentment and anger directed at the parents by the child. Intensive work with both revealed that the child felt cheated, resentful, angry and alienated by the top-down approach, which manifested as difficult behaviours once the child was reunified which in some cases led to post-placement breakdown. Based on this finding, we developed a joint case management tool-set and process flow including Child Participation as a wellbeing domain with suitable sub-indicators. Consequently this has had a beneficial impact on reunification placements, as well as prevention cases. This is exemplified by the cases below that were encountered by One Child One Family HHC SA.

Naledi, a 16 year old girl, was placed in an institution as result of an unwanted teen pregnancy at 13 years old. She spent three years in the institution prior to being reunified with her biological family. Post-placement, Naledi's parents reported difficult and uncontrollable behaviours, including refusal to adhere to household rules and being aggressive and rude to her parents. After intensive counseling sessions, we learned that Naledi's anger and frustration resulted from not being allowed to participate in discussions between the case manager and her parents and possibly prevent the decision to place her in the institution. She said that the case manager had consulted with her parents and had not given her any opportunity to contribute to the discussions. She said that spending three years in the institution had damaged her education as well as being harmful to her emotionally. As the work progressed, Naledi's parents reported a positive change in her behaviour. We continued to support Naledi and her parents with a less intensive programme of counseling. The case manager also said that she had learned the importance of real participation from this case and is now actively promoting participation to her colleagues.

Gugu is a 12 year old girl living with her single mother. Gugu struggles at school and is often in trouble for not completing her homework and assignments. Gugu's mother Lerato thinks she cannot help Gugu with the school work and fears that Gugu will drop out of school unless she has strong supervision at home after school. She contacted the case manager and asked her to place Gugu in an institution where she would have proper supervision and would be better able to complete her school education. At the request of the case manager, we completed the relevant assessments and Gugu participated in an evaluation by an educational psychologist. Gugu was diagnosed with dyslexia and attention deficit disorder. With continuing psychologist interventions, and counseling for Gugu and between Gugu and her mother, she has done very well. Once Lerato understood that Gugu has a medical condition which is treatable and can be managed, she became much more supportive of Gugu. Gugu is less frustrated by the impact of her condition on her school work and feels supported by her mother. Gugu's school teacher is also more supportive and has set aside two hours a week to help Gugu with school work, especially mathematics. This support helped considerably and Gugu passed the year with a good mark, graduating to high school. In this case, the positive outcome of real participation and communication between all parties is demonstrated. There is no residual anger or resentment between Lerato and her daughter, and the treatment regime for Gugu has had a positive outcome on her ability to complete her school work successfully. The family is close-knit and supportive of each other.

The outcomes of targeting the mandated right of children to participate in care decisions have been positive. In the 3rd phase of work where Gauteng Provincial Department of Social Development are the implementing partners in care reform, there have been no post-placement breakdowns and to date, 56 prevention cases have been successfully concluded. Where 'difficult and uncontrollable behaviours' have been a major push factor in the institutionalisation of children, this factor has been minimised through facilitation of participation and agency of children at risk in case management and placement decisions.

Recommendations

YADIS partners propose the following recommendations to strengthen State-led care reform processes with particular regard to accountability, participation and inclusion:

1. States must ensure **inclusive care reform** and lead a strategy for planned progressive deinstitutionalisation. States should pay special attention to ensure that children with disabilities are not left behind in national policy and programmes for care reform and deinstitutionalisation, and that inclusive child protection and care systems are equipped with mechanisms that meet the challenges of all types of differences including disability. Care reform must include reintegration of children with disabilities placed in facilities, including hospitals, psychiatric facilities, rehabilitation and 'special schools'. States should ensure that all family strengthening, prevention and alternative care options respect the rights of all children, including children with disabilities.
1. States must guarantee **full participation of all children and care leavers in decisions about their care, including children with disabilities**. Each care decision must be based on the best interests of each individual child, ensuring that all children and those who support them including families and representatives of persons with disabilities are involved in any decisions that affect them, and that the views and preferences of children are fully considered. States must ensure that children are informed, supported to understand and participate, and listened to at all stages of their care planning, placement decision making, transition and monitoring. States should develop comprehensive, appropriate and inclusive case management processes and mechanisms and invest in the capacity of its social workforce to engage children in their care planning and placement decision processes.
2. States must provide **inclusive communication** strategies, tools and capacities and provide age appropriate and disability-related support to children with disabilities to participate in decision-making about their care. This requires that States address communication barriers and create inclusive participatory environments - including in court proceedings. States

must ensure that all children are provided with relevant, accessible and appropriate information, spaces for engagement, and safety to express their views about their care. States must ensure inclusive communication through accessible formats and technologies and support the use of sign language, Braille, augmentative and alternative communication, and modes and formats of communication chosen by children with disabilities.

3. States must ensure that the child protection and care system is **accountable to children**. States should create space for children, adolescents and young people to share their experiences and to shape national strategies and plans for care reform. States should actively involve children in care and young people with lived experience of care, including those with disabilities, in the development, implementation and monitoring of policies, programmes and plans. States should design accessible reporting, redress and complaints mechanisms for all children.
4. States should urgently prioritise **inclusion of children with disabilities across all sectors**. Family and community based care for children with disabilities can only be achieved when inclusion is ensured across services provision including health and education. States should address knowledge, attitudes and practices regarding children with disabilities at family and community level, build the capacity of the workforce to realise children's rights to participation and inclusion particularly in the social welfare, health, justice, and education workforce, and invest in inclusive service provision.
5. States should **invest** in participation, accountability and inclusion and allocate budgets to ensure that participation is meaningful and inclusive, and that it informs individual care decisions.