

# YOUTH ACCOUNTABILITY AND DISABILITY INCLUSION IN SOUTH AFRICA (YADIS)

**Research Brief** 

# YOUTH ACCOUNTABILITY AND DISABILITY INCLUSION IN CHILDREN'S CARE

We must empower young people to create and change systems that care for them. It's the only way to make care systems that truly nurture, not harm.

But how to do it, when weak policies and tokenistic practices around disability inclusion and youth participation are stifling real empowerment? Why should a broken care system require the most vulnerable, the most affected, to do the hard work of changing it?

It shouldn't. Meaningful empowerment, inclusion and accountability are possible. Young people's authentic voices can drive care reform. They can create a world where the demand for inclusive access to comprehensive support within their communities is heeded.

In 2022, South African children and young people, including those with a disability or at risk, told their own stories, as part of our Youth Accountability and Deaf Inclusion in South Africa (YADIS) project.

They show that they have something important to say, and that we can make space to listen to them. We can make it easy for them to speak. And we can deconstruct the environments and power imbalances that keep them silent or ignored, so young people can effect change for themselves. Now it's up to us - development agencies, universities and governments - to support them to do so.





#### Research partnership for youth accountability and disability inclusion

Hope and Homes for Children is at the forefront of a growing global movement to eliminate the institutional care of children. Through our research, advocacy and practice we are addressing issues of youth accountability and disability inclusion as it relates to vulnerable children who are in care or at risk of family separation. We know that across the world weak policies and practices regarding disability inclusion and youth accountability are roadblocks to care reform.

However, meaningful empowerment, accountability and inclusion is possible as demonstrated by our Youth Accountability and Deaf Inclusion in South Africa (YADIS) research which enabled young people to tell the story they want to tell. We joined forces with University of Leeds, University of Pretoria, One Child One Family HHCSA, Bishop Simeon Trust, DeafKidz International and Thrive in a unique research partnership, with a focus in South Africa. We implemented the Youth Accountability and Deaf Inclusion in South Africa (YADIS) project under the umbrella of the participatory arts programme Changing the Story, and funding from the UK Arts and Humanities Research Council and the Global Challenges Research Fund.

YADIS was a multi-layered research project centred around an inclusive youth leadership project which was designed to support vulnerable children in four communities in Gauteng and Western Cape Provinces, South Africa to claim a greater voice within their communities. YADIS combined 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 communities. We carried out a scoping review of the literature on youth development to contextualise and enhance the youth leadership project and provide a firm basis on which to build our participatory action research and learning. We undertook targetted research to measure changes in youth perspectives regarding their own agency.

Together, this research aimed to inform international policy debates on child protection and disability rights, guide policy on the development of structures and supports for inclusion of vulnerable children in South Africa in the planning and implementation of processes which impact their lives, and enhance the current work of NGOs to develop more inclusive practices. Our research points to how the voices of vulnerable children and young people, including those living with disability, can make a difference as authentic agents of change in their communities, to drive care reform and ensure inclusive access to comprehensive, responsive and efficient service-delivery and support in communities.

The key activities and findings are summarised on the following page, followed by a deeper dive into the literature, action, and evaluation within the YADIS project and our recommendations for child care system reform.

"IT WILL BE IMPOSSIBLE TO DELIVER ON THE UN SUSTAINABLE DEVELOPMENT GOALS (SDGs)
WITHOUT WORKING IN PARTNERSHIP WITH CHILDREN AND YOUNG PEOPLE, AND IN PARTICULAR
WITHOUT UNDERSTANDING HOW THEY SEE THE WORLD AND HOW THEY WISH TO APPROACH
THE CHALLENGES FACING US ALL." Professor Paul Cooke, University of Leeds—YADIS Principal Investigator



Research component	What we did	What we learnt
SCOPING REVIEW	A scoping review of the literature on youth engagement, accountability, disability and care undertaken with the Centre for Augmentative and Alternative Communication at the University of Pretoria¹.  Analysis of how youth development programmes are meeting the needs of vulnerable youth, in order to inform how youth accountability can be increased within child care and protection systems.  Provided a firm basis on which to build our participatory action research in South Africa, and informed its evaluation.	Exclusion of young people from voice, agency, and leadership remains common, and genuine accountability to children is rendered impossible as the structural environments and relationships of power around them are ignored.  Youth leadership programmes typically focus on one of four areas: youth, relationships, community, and social justice. Youth focus is most common, and social justice focus is least represented.  Multidimensional considerations across these dimensions are generally absent, and yet are critical to provide children and young people with both the skills to engage with and opportunities to change their circumstances. For youth to be able to drive change, additional opportunities at the community and broader society levels are required.  Multi-sectorial, holistic, relational, multi-layered approaches required. Active involvement of youth in both planning and implementation of programmes is necessary.  Strong correlation between the amount of authority bestowed/taken by young people in programmes and positive development outcomes.  Paucity of guidelines on supporting vulnerable and marginalised youth, or attention to disability inclusion. Safeguarding must be highlighted in any program working with vulnerable youth.
ACTION RESEARCH	Designed and implemented a youth leadership development model inclusive of deaf and hearing children and young people in South Africa (YADIS).  Participatory-arts project combined community development, arts-based leadership and participatory	Participatory arts and youth-led project development can enable young people to tell the story they want to tell.  Improving inclusion of children with disabilities in youth leadership work requires investment in resources and skills especially with regards to safeguarding, community integration, and accessible communication.

<sup>&</sup>lt;sup>1</sup> Bastable et al, 2021



filmmaking, inclusive communication, knowledge exchange and advocacy for youth accountability and inclusion. Emphasis on positively fostering integration of deaf and hearing children.

Challenging power relations through alternative approaches requires a sensitive and holistic approach.

Safeguarding is a crucial and complex issue in relation to accountability, participation and inclusion. Risk must be carefully assessed and comprehensive safeguarding knowledge, skills and mechanisms put in place when working towards platforms and processes to enable true expression and amplification of 'voice'.

**EVALUATION** Evaluation of YADIS youth leadership programme in South Africa undertaken with the Centre for Augmentative and Alternative Communication at the University of Pretoria.

> Used Q-method participatory research methodology enabling youth to report their perspectives of their skills and opportunities.

> Prioritised safeguarding and inclusion as key components of research process.

Yielded insights into changes in children and young people's perceptions of themselves and their agency, and in relation to their communities and the broader country at large.

YADIS resulted in significant changes in perceptions of the youth and their own agency, including increases in perceptions of empowerment within the community.

Vulnerable and Deaf youth began the programme with differing perceptions of self, community and society, but showed similar perceptions on the completion of the programme.

Changes in the youths' perceptions suggest broadening perspectives, increased awareness of others and their own needs. Youth gained insight into themselves as individuals who could guide others through sharing their experiences and contribute to their communities.

YADIS is heading in the right direction to facilitate youth participation and agency in issues that affect their lives, however further emphasis on broader society is still required.

Safeguarding risks are heightened in research with children and youth who are vulnerable or living with disabilities, requiring careful assessment of and response to safeguarding needs.

Further opportunities for increased agency and strengthening the youth's perceptions of themselves as changemakers in broader society were realised within the YADIS project but missed out of the timeframe and scope of this evaluation.



#### Why does accountability and inclusion matter for children?

Children and young people are directly affected by systemic issues, yet they are too often absent in the processes of decision-making and planning for the societies they will ultimately inherit.

Vulnerable children are routinely excluded from decisions about their lives.

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 they 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 about their care and adult-led considerations of the 'best interests of the child' prevail, with children frequently separated from their family without fully understanding why, or without being given a chance to express their opinions about their care. Lack of inclusion is largely 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 willingness on the part of decision makers to take on board children's feedback in order to achieve improved outcomes<sup>2</sup>

# "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."

Children with disabilities are further excluded - including through legal restrictions and through lack of accessible and appropriate information and communication barriers among others<sup>3</sup>. This includes those that are deaf who lack access to communication in their mode of choice - sign language or sign supported spoken language. This is particularly important as children with disabilities are overrepresented in residential institutions. 1 in 3 children living in institutions have disabilities - compared with 1 in 6 of the world's population<sup>45</sup>. They are exposed to significant violence within institutions, at heightened risk of physical, emotional & sexual abuse, neglect & exploitation<sup>6</sup>. Driven by stigma and discrimination, children with disabilities are excluded from families and communities<sup>7</sup> - being more likely to experience physical and sexual violence and neglect than their peers<sup>8</sup> and at increased risk of gender-based violence<sup>9</sup>. The lack of robust, reliable and comparable national data on children with disabilities poses a challenge to the delivery of inclusive programmes and services.

<sup>&</sup>lt;sup>©</sup> 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.



<sup>&</sup>lt;sup>2</sup> Kay, E., & Tisdall, M. Conceptualising children and young people's participation: Examining vulnerability, social accountability and coproduction. International Journal of Human Rights, 21(1), 59–75. 2017.

<sup>&</sup>lt;sup>3</sup> Lansdown, G., Berman Bieler, R. and Mitra, G. 2013. TAKE US SERIOUSLY! Engaging Children with Disabilities in Decisions Affecting their Lives

<sup>&</sup>lt;sup>4</sup> United Nations, General Assembly, 'Global Study on Children Deprived of Liberty', A/74/136, 2019.

<sup>&</sup>lt;sup>5</sup> World Health Organization, 'World Report on Disability'. 2011

<sup>&</sup>lt;sup>6</sup> 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.

<sup>&</sup>lt;sup>7</sup> United Nations General Assembly 'Status of the Convention on the Rights of the Child' A/73/272. 30 July 2018

<sup>&</sup>lt;sup>6</sup> 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.

In South Africa, the legislative and policy environment is relatively favourable yet a critical gap exists in practical alignment and implementation. The Children's Act No 38 of 2005<sup>10</sup> and allied policy frameworks, National Disability Policy<sup>11</sup> and subsequent White Paper on the Rights of Persons With Disabilities<sup>12</sup> confirm and reaffirm the social inclusion of persons living with disability, the need to have the child at the centre of the decision making process and that residential institutions for children are a last resort. Yet this is rarely adhered to, in particular for vulnerable children who are orphaned, at risk of family separation or are in the care system, children with disabilities and children with disabilities who are in care. Despite advanced human rights policies and legislation, children and young persons with disability in South African communities and institutions continue to experience marginalisation, discrimination and neglect and their lived experience is that of disempowerment, disenfranchisement, inequality, neglect, invisibility, harm, prejudice, abuse and disregard. The absence of adequate socio-economic service delivery and the de facto exclusion of children and young persons with disability from the greater majority of NGO and CBO-led programming, means that many are committed to institutional care and 'special schools' with a residential component, in a frustration-driven attempt by under-supported parents / carers to access necessary developmental and support services. Compounding this is the societal prejudice and bias against persons with disability which makes social integration complex and, often, dangerous for these children and young people.

#### What does the literature tell us? A Scoping Review on Youth Development.

The Centre for Augmentative and Alternative Communication at the University of Pretoria led a scoping review of the literature on youth engagement, accountability, disability and care¹ which aimed to better understand if existing youth development programs are meeting the needs of vulnerable youth in order to inform how youth accountability can be increased within child care and protection systems.

#### Findings:

- Youth leadership programmes for vulnerable and at-risk children focus on four areas: youth, relationships, community, and social justice-focused development. Youth focus is commonly represented, and social justice focus is least represented. Most programs addressed only one focus area and multidimensional considerations were generally absent.
- If youth development programs are genuinely going to provide children and young people
  with both the skills to engage with and opportunities to change their circumstances, then all
  four of these focus areas need to be addressed.
- Empowerment of youth through participation is most successful when it is multi-sectorial. Need for an holistic, 'relational', multi-layered approach.
- There is strong correlation between the amount of authority bestowed/taken by young people in relevant programmes and positive development outcomes. Active involvement of youth in both the planning and implementation of programs is necessary.

<sup>&</sup>lt;sup>15</sup> Government of the Republic of South Africa. Department of Social Development. White paper on the Rights of Persons With Disabilities. 2016.



<sup>&</sup>lt;sup>10</sup> Government of the Republic of South Africa. Children's Act No 38 of 2005.

<sup>&</sup>lt;sup>†</sup> Government of the Republic of South Africa: National Disability Policy, 2015

There is a paucity of guidelines on supporting vulnerable and marginalised youth.
 Safeguarding must be highlighted in any program working with vulnerable youth.

Overall, genuine youth empowerment, participation, voice and leadership is widely lacking. Programmes to support youth development and participation of children and young people are often tokenistic because the structural environment and relationships of power around the child are ignored.

### KEY RESOURCE: How Are Leadership Programs Empowering Our Vulnerable Children and Youth? A Scoping Review.

Bastable K, Cooke P, Harvey L, Olarte V, Zimmerman J, Dada S. How Are Leadership Programs Empowering Our Vulnerable Children and Youth? A Scoping Review. Social Sciences. 2023; 12(1):2. https://doi.org/10.3390/socsei12010002

#### Action Research: Participatory Arts for Change in South Africa

YADIS took an action research approach to develop an inclusive youth leadership programme for vulnerable children in four communities across Ekurhuleni, Gauteng Province and Hanover Park, Western Cape in South Africa so that they may claim a greater voice within their communities. The overarching goal was to guide and support service delivery through accountability to children and young people. Hope and Homes for Children – One Child One Family South Africa (HHC-OCOFSA) worked in partnership with a number of community based youth centres (Safe Parks), educational

facilities, the Department of Education and local NGOs Thrive, Bishop Simeon Trust and Deafkidz International.

Together we adapted and implemented the 'Changing the Story -Leadership Development Programme' (CTS-LDP) arts-based programme under the leadership of University of Leeds — with core adaptations for YADIS focusing on inclusion of deaf children and safeguarding of vulnerable youth. This aimed to develop youth leadership skills and foster the inclusion and integration of deaf and hearing children, thus developing their self-advocacy skills and providing important psycho-social, educational and careers support in the process, helping them to become active participants and agents in civil society and to advocate for better and more inclusive services in their communities.

#### **YADIS IN NUMBERS**

- **26 hearing children**
- 22 deaf children
- 48 workshops
- 20 weeks youth leadership
- **26 comics**
- 3 films
- 4 showcasing events





The core of the CTS-LDP is the use of film production as a mechanism through which the youth can experience collaboration, express one's views, process challenging life circumstances, experience reflective learning and showcase their capabilities. In addition to participatory arts, workshops are also held on gardening, business and financial literacy, general educational support, and sports.

With youth voice and youth-led design at the centre, significant time was dedicated to workshops and activities to reduce community stigma and foster knowledge, understanding, relationships and communication between deaf and hearing children. The young people selected a Youth Leadership Committee to spearhead the group, and prioritised inclusive communication such as using South African Sign Language and non-verbal communication (such as Whatsapp).

Safeguarding was prioritised, with adaptation and strengthening of our safeguarding policy, protocols, mechanisms and training given the risk environments in South Africa and the specific needs of deaf and vulnerable children and youth. The youth groups developed a Safeguarding Charter to ensure "all the children and young people participating in this project have the right to feel safe at all times and that the adults guiding the project take the collective responsibility to protect this right". Safeguarding training was provided to all staff, and all children and youth were trained in the processes and procedures in place to protect them and how they could report any concerns. Specific safeguarding needs for the Deaf youth included the provision of "safe" adult who they could contact who were accepted and trusted by them and able to converse in South African Sign Language, as well as non-verbal contact options such as Whatsapp. Safeguarding was a crucial and complex issue in relation to accountability, participation and inclusion, requiring a thorough assessment of previously unexplored safeguarding dimensions and comprehensive safeguarding knowledge, skills and mechanisms to be put in place in order to safely work towards platforms and processes to enable true expression and amplification of 'voice'.

With strong foundations in place, the 20-week youth leadership programme focused on youth collaboration through grassroots comics and participatory filmmaking. We introduced children and



young people to different arts-based practices that develop their skills, enable them to understand and express their experiences and to use critical analysis to identify resolution strategies for social issues in formats that can be shared. The groups prepared grassroots comics to sketch out a range of issues that young people in their communities face, which became the starting point for a collective decision making process, with the group exploring why they want to make a film, the issue they want their community to think about and who should see it. Through a series of filmmaking workshop the children and youth lead their own script development, shooting, sound design and editing. They then led a community showcasing event for children, families and communities to watch the films and engage in conversation around them.

We found that improving inclusion of children with disabilities in youth leadership works requires significant investment in resources and skills -



especially with regards to safeguarding, community integration, and accessible communication. Participatory arts and youth-led project development can enable young people to tell the story they want to tell – but challenging power relations through alternative approaches requires a sensitive and holistic approach. Several layers of advocacy and engagement within YADIS are discussed below, as these were critical in opening channels for children to use their voice and agency to influence the decision-makers and systems around them.

#### Advocating for change

Supporting vulnerable children and young people to explore their own agency and begin to drive the changes they want entailed youth-led advocacy at local, national and global level. Recognising that teaching and supporting children and youth to share their voices between peers does not lead to structural change, we focussed on supporting youth to share their voices in their communities and with the structures and decision-makers who have the means to make change happen directly. Supporting deaf children to self-advocate and self-represent through engagement with communities and policy structures was particularly important.

#### This included:

- **Child-Parent Reflection Sessions** supporting family communication and resilience to enable children to communicate and influence within their everyday settings.
- Community Showcasing changing local perceptions of what young people can do and
  raising key issues locally, through showcasing of the participatory films developed by
  children and young people.



#### Youth-led policy-level advocacy in South Africa.

- National Association of Child-Care Workers
- Gauteng Department of Social Development a meeting between youth engaged in YADIS and government officials and decision-makers on 21 September 2022 enabled deaf and hearing children and young people to communicate their issues, express opinions and propose solutions to provincial authorities and decision-makers.
- **Global advocacy for care reform** learning from YADIS and the experience of accountability and inclusion in care system reform in South Africa informed the UN Day of General Discussion on Child Rights and Alternative Care<sup>13</sup>.

As a result in Hanover Park, one of the young people who was part of the YADIS project has since been employed by the Children's Commissioner Western Cape as a youth commissioner, opening to them an opportunity to shape official policies, programmes and responses to issues affecting children across the province.

"TEACHING YOUTH TO 'SHARE THEIR VOICES' ONLY BETWEEN PEERS DOES NOT ALLOW FOR THE FACILITATION OF CHANGE. BUT TEACHING YOUTH TO SHARE THEIR VOICE IN THEIR COMMUNITIES AND STRUCTURES NOW INTRODUCES THEIR VOICES TO THE PEOPLE WHO HAVE THE MEANS TO MAKE THE CHANGE." Professor Paul Cooke, University of Leeds — YADIS Principal Investigator

### KEY RESOURCE: YADIS Submission to the UN Day of General Discussion on Child Rights and Alternative Care

Hope and Homes for Children, University of Leeds, University of Pretoria, One Child One Family HHCSA, Bishop Simeon Trust, and DeafKidz International. "Inclusion and carticipation make the difference in children's care. Youth Accountability and Disability Inclusion in South Africa (VADIS)"

#### Youth perceptions of their own agency: An evaluation

Our research with the University of Pretoria sought to evaluate the YADIS project, specifically the participatory-arts youth leadership programme, in terms of the changes to the children and young people's perceptions of themselves and their agency, and in relation to their communities and the broader country at large.



<sup>&</sup>lt;sup>18</sup> Hope and Homes for Children, University of Leeds, University of Pretoria, One Child One Family HHCSA, Bishop Simeon Trust, and DeafKidz International. Inclusion and participation make the difference in children's care; Youth Accountability and Disability Inclusion in South Africa (YADIS). 2021

A Q-method research design was selected as the participation of vulnerable youth is at the very core of this study. The Q-method is a participatory research methodology that enable the youth to report their perspectives of their skills and opportunities.

Safeguarding of participants formed a key component of the research process. This began with ethical approval granted by the University of Pretoria, the University of Leeds and the Gauteng Department of Education. Informed consent was obtained from all youth and their caregivers and permission was provided by the principal of the school of the Deaf. A Safeguarding Charter was developed by the YADIS project team, all staff were trained in safeguarding and all children and young people were trained in their rights and the safeguarding processes, procedures and reporting mechanisms in place to protect them. To support the safeguarding and participation of deaf youth, research implementation included designated, trusted adults who were able to converse in South African Sign Language.

Results<sup>14</sup> provided evidence of significant change in specific perceptions of the youth and their own agency, including increases in perceptions of empowerment within the community. Vulnerable and Deaf youth began the programme with differing perceptions of self, community and society, but showed similar perceptions on the completion of the programme.

Such changes in the youths' perceptions speak to a broadening of their perspective, with increased awareness of others and their own needs. Youth gained insight into themselves not only as individuals, but as individuals who could guide others through sharing their experiences and contribute to their communities.

Although the two groups of vulnerable and Deaf youth began their journey with differing perceptions, after the programme they now share perceptions to a greater extent – with both groups having strong positive perceptions about being a leader and being happy with ones–self, while Deaf youth also reported strongly on individual skills such as being able to set and achieve goals and having self-worth. This broadening of perspective has been shown in other programmes to impact career decisions as well as building the capacity of the youth to impact social change beyond the programme<sup>1516</sup>.

The evaluation suggests that YADIS is heading in the right direction to facilitate youth participation and agency in issues that affect their lives, however further emphasis on broader society is still required. This was impacted by funding challenges experienced during the project, shortening of project timelines and evaluation limitations which resulted in the policy events and later opportunities which could have increased agency and the youth's perceptions of themselves as changemakers in broader society being missed out of the timeframe of this evaluation. For example, the youth self-advocated and self-represented through engagement with policy structures and one of the young people has since been employed by the Children's Commissioner Western Cape as a youth commissioner. Participant feedback also indicated multiple challenges around disability inclusion, including that hearing children could have been taught some basic sign

<sup>&</sup>lt;sup>16</sup> T Schusler, A Krings, & M Hernández. Integrating youth participation and ecosocial work: New possibilities to advance environmental and social justice. *Journal of Community Practice*, 27(3–4), 460–475. 2019.



<sup>&</sup>lt;sup>14</sup> K Bastable, P Cooke, V Olarte, D Casteleijn & S Dada. Changing the Story: Evaluation of a leadership development programme for vulnerable and Deaf youth in South Africa. Submitted for publication, 2023.

<sup>&</sup>lt;sup>15</sup> C Nicholas, H Eastman-Mueller, & N Barbich. Empowering Change Agents: Youth Organizing Groups as Sites for Sociopolitical Development. *American Journal of Community Psychology*, 63(1–2), 46–60. 2019.

language as they felt unable to communicate with the deaf children without having sign language interpreters present, and the need for further sustained support over a longer time period.

## KEY RESOURCE: Changing the Story: Evaluation of a leadership development programme for vulnerable and Deaf youth in South Africa.

K Bastable, P Gooke, V Olarte, D Casteleijn & S Dada. 'Changing the Story: Evaluation of a leadership development programme for vulnerable and Deaf youth in South Africa'. Submitted for publication, 2023. Contact for details.

#### Shifting power and accountability in care reform

Residential 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** and **be accountable to them**. The transition towards 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. Within this, it is clear that 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. As highlighted in the YADIS research, engagement and empowerment must happen not only between children in the care system, but between care-experienced children and young people and the institutions, communities and structures which govern their lives.

#### Recommendations for inclusive and accountable care reform

YADIS partners propose the following global recommendations to governments and development partners to strengthen care reform processes with particular regard to accountability, participation and inclusion:

1. Ensure that **inclusive care reform** is rooted strategies and plans progressive deinstitutionalisation that pays special attention to ensure that children with disabilities are not left behind, 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 residential facilities, including hospitals, psychiatric facilities, rehabilitation and 'special schools'. All family strengthening, prevention and alternative care options respect the rights of all children, including children with disabilities.



- 2. 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. 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.
- 3. 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 addressing communication barriers and creating inclusive participatory environments including in court proceedings. Ensure that all children are provided with relevant, accessible and appropriate information, spaces for engagement, and safety to express their views about their care. 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.
- 4. Ensure that the child care system is **accountable to children**. Create space for children, adolescents and young people to share their experiences and to shape national strategies and plans for care reform. 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.
- 5. 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.
- 6. **Invest in participation, accountability and inclusion** and allocate budgets to ensure that participation is meaningful and inclusive, and that it informs individual care decisions.





#### A research partnership for youth accountability and disability inclusion

Hope and Homes for Children, the University of Leeds, University of Pretoria, One Child One Family HHCSA, Bishop Simeon Trust, DeafKidz International and Thrive joined forces in a unique research partnership to support youth accountability and inclusion in South Africa. This was under the umbrella of the participatory arts programme Changing the Story, and funding from the UK Arts and Humanities Research Council and the Global Challenges Research Fund.

Research briefing written by Victoria Olarte, Senior Partner – Strategic Research, Hope and Homes for Children. Please contact for further information – victoria.olarte@hopeandhomes.org

