

# **PARENTAL EMPOWERMENT AND ENGAGEMENT IN NURTURING POTENTIAL OF CHILDREN WITH DISABILITIES**

**Kenya Institute of Special Education.**

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## **ABSTRACT**

This report summarises keynote speeches, presentations and findings of research papers/projects, key discussions, recommendations, conclusions and way forward of the 4th National Conference on Parental Empowerment and Engagement in Nurturing Potential of Children with

Disabilities held in Nairobi, Kenya, on 23rd and 24th, November 2022. The conference was organised by Kenya Institute of Special Education (KISE) in collaboration with the Ministry of Education with support from development partners, sponsors and other key stakeholders.

## **INTRODUCTION**

Kenya Institute of Special Education (KISE) in collaboration with the Ministry of Education (MoE) organized the 4th KISE National Conference. The Conference was held on 23rd and 24th November 2022. The conference theme was, “Parental Empowerment and Engagement in Nurturing Potential of Children with Disabilities”.

The conference which was one of a kind to be held at KISE and was sponsored by various donors, aimed to create a platform to have a discourse on parenting children with special needs and disabilities. This conference drew the roadmap towards enhancing capacity of parents of learners with disabilities to be more involved in their children’s learning and development. The Competency Based Curriculum (CBC) principle of parental empowerment and engagement requires more focus by education stakeholders. Parental empowerment and engagement plays a critical role in holistic development of a child.

The education system in Kenya addresses relevance, equity, equality and inclusion. This is in line with the SDG4 to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all. This conference brought together Educationists, Researchers, Scholars, parents and Development Partners among others who deliberated on experiences, current trends, and practices in Parental Empowerment and Engagement.

### **The conference had 6 areas of focus namely:**

- Family Engagements, Parents role in assessment and interventions for learners with disabilities.
- Parental engagement in planning for transition of learners with disabilities.
- Support for parents and Caregivers of learners with Disabilities.
- Awareness and advocacy on rights of learners with disabilities.
- Community Involvement in Inclusion of learners with Disabilities.
- Parenting Children with special needs and disabilities: Experiences and challenges.

This conference was both blended (physical and online) which aimed at providing a national and international scholarly platform for professionals, researchers, special needs education experts, teachers, parents, policy-makers and other stakeholders to discuss on parenting

children with special needs and disabilities. It was anticipated that the deliberations thereof will inform best approaches to parental empowerment and engagement in education of their children.

## **Background**

Kenya as a member of the United Nations is considered a regional leader in establishing progressive initiatives towards the realization of Sustainable Development Goals (SDGs). To ensure inclusive and equitable quality education and to promote lifelong learning opportunities for all as stipulated by SDG4, Kenya has established an education system that addresses relevance, equity, equality and inclusion. In 2017, the government embarked on the most comprehensive education reforms since 1981, which has seen the introduction of CBC guided by the following six principles: (1) opportunity for learners; (2) excellence and competitiveness instead of competition; (3) diversity and inclusion; (4) differentiated curriculum and learning; (5) parental empowerment and engagement; and (6) Community service learning.

Principle number 5 on parental empowerment and engagement has received little focus by education stakeholders, yet it plays a critical role in holistic development of a child. For learners with disabilities for instance, parental empowerment and engagement is core in nurturing their potential. According to Muigai (2018), parents are eager to participate in their children's education despite the numerous challenges they encounter, including lack of know-how on how to get involved.

In Kenya, several researches and documentations have been done on education reforms and policies, but very little evidence-based research is available in regard to parental empowerment and engagement as a guiding principle in addressing education of children with special needs and disabilities. Being a leader in modelling best practices for inclusive education, KISE convened a conference around the theme 'Parental Empowerment and Engagement in Nurturing Potential of Children with Disabilities.

## **Conference Objectives**

- To establish the level of parental empowerment and engagement of parents for children with disabilities
- To explore policies and practices promoting parental empowerment and engagement.
- To create awareness on collaboration and partnerships between parents, community and other stakeholders in nurturing potentials of children with disabilities.
- To share ideas and experiences in nurturing potentials of children with disabilities

## **Conference Chairperson**

The chairperson of the conference Mr. Mweu, welcomed all participants to the conference. He explained that participants were expected to deliberate on how parents could be supported to take care of their children with disabilities. Further, the government's role and that of the community shall be discussed.

### **Highlights**

- When a family gets a child with disability there are subsequent reactions which range from acceptance to rejection.
- Parents of children with disabilities experience challenges during the upbringing of their children.
- In most cases, many parents do not know how to support their children or where to get the much-needed support.
- Parents have in most cases delegated much of their roles to teachers due to lack of requisite skills and knowledge on how to support their children with disabilities.
- Family is the basic critical unit expected to provide socio-economic support to children with disabilities. Parents and immediate families need empowerment to be able to provide the necessary support.
- The 2022 conference theme of Parental Empowerment and Engagement emanated from the critical role played by parents of children with disabilities in nurturing their children's potential.
- Participants were called upon to engage and discuss freely to inform improved services to children and persons with disabilities in general.

### **The Deputy Director Programmes, KISE**

The Deputy Director Programmes, KISE urged everyone to support children with disabilities. The director expressed desire that the two-day conference would make people network, learn from each other and rededicate to serving children with special needs and disabilities in a better way.

### **Director KISE**

The director welcomed all participants to the conference and gave a brief about the services offered at the institute which include: training, research, functional assessment and rehabilitation among others. He said that every child can learn. However, all children do not learn in the same way. He congratulated parents of children with special needs and disabilities for the good work they are doing in parenting their children and urged them on.

### **Presentation Highlights**

- The Rehabilitation Centre in the Institute has been ranked Level 6 by the Ministry of Health.
- Services offered at the services are affordable and encouraged all to create awareness about it.
- He urged everyone to participate actively in the conference and come up with recommendations to improve policy and practice in service provision for children with special needs and disability.

### **Chief Guest**

The Permanent Secretary Ministry of Education represented the Cabinet Secretary for education who was the chief guest. He appreciated all participants and invited guests from various sectors and countries. He noted that, the theme of the conference '*parental empowerment and engagement in nurturing children with disability*' is timely.

### **Presentation Highlights**

- The roles of parents and care givers of children with disabilities cannot be underestimated.
  - He implored delegates to positively engage during the conference to provide MoE with recommendations that will inform policy.
  - He assured participants of the Government's commitment to promotion of education for all through implementation of the sector policy on education of learners and trainees with disabilities 2018.
  - He emphasized KISE's mandate to conduct training, research, functional assessment for early intervention, production of resources and assistive devices for learners with special needs and disabilities.
  - He assured participants that MoE will continue to support research in special needs and related areas.
  - He noted that the Assessment and Research centre in KISE offers therapy to children with special needs and promotes inclusive educational practices.
  - He noted that KISE has been organizing conferences since the year 2016 and this conference will build on the achievement of previous conferences.
- This conference is critical in underscoring the government's recognition of parents' involvement in their children's.

The Permanent Secretary encouraged participants to freely discuss the prevailing and emerging issues regarding parental empowerment and engagement. He motivated participants to share experiences and knowledge to ensure that all leave feeling encouraged and strengthened.

### **Keynote Address: Founder of Andy Speaks for Special Needs Persons Africa**

The presenter is a parent to two children with autism. She is also a Director at the board of National Council of Persons with Disabilities and a representative of care givers of persons with neurodevelopmental disabilities.

She expressed the fact that disability is diverse. There is physical disability, neuron-developmental and mental disabilities. Each disability presents different difficulties and hence, a caregiver's journey is never easy at all.

### **Presentation Highlights**

- There are many limitations and barriers in the community that make it hard for children with disability to access services. As a parent with special children, you have to advocate and also tell people that our children need to be considered.
- Some children with disabilities are non-verbal meaning they cannot express themselves, thus caregivers have to learn how to communicate with them through their special language.
- When enrolling them in school, there is always need for extra support for children with disabilities in all areas since they need special attention unlike the other children.
- She reported that when the doctor breaks news about a child's condition using medical jargon such as autism or spina bifida (terms you never heard), a parent goes through turmoil with mixed feelings; emotions, expectations, heartbreaks and denial. It gets more challenging when asked tough questions like; "Who in your family has this?"
- She noted that there were only twenty-three (23) neurologists in Kenya. This makes it hard for them to serve the large population.
- She pointed out that there is lack of statistics of children with disabilities.
- Occupational and speech therapy are very engaging and a lot of patience and understanding is needed for both the caregiver and medic.
- Some children with neuro-diversity have coexisting conditions such as epilepsy, obsessive compulsive disorder (OCD), attention deficit and hyperactive disorder (ADHD) and attention deficit disorder (ADD).
- Some parents face rejection. Some are blamed even by spouses. In most cases, mothers get blamed and are eventually left on their own.
- Taking care of a child with disability takes toll on a single parent who is already into depression caused by denial and betrayal from family members. It takes too much time seeking help which often comes late.
- She noted that it is usually a long journey towards acceptance and therefore, early intervention can mitigate the situation.
- As a parent, it is usually a painful experience when your agemate's children achieve critical milestones and wonder why yours is not.
- Some children with disabilities go through suffering and frustrations when playing and interacting with others.
- In some cases, some parents of children with disability are labelled as bad parents.

- She observed that equity is not having a level play field but meeting at one's point of need.

She concluded by encouraging parents to educate themselves and be aware of the opportunities available for them. Funds for persons with disability are there but many parents don't show up to claim it. Some don't even know if it exists and there is need to create awareness about services available and how they can be accessed.

## **Parallel Session 1**

### **Panel 1: Family Engagement in Educational Interventions and Parental Engagement in Planning for Transition of Learners Disabilities**

#### **Parents Support to Their Children through Therapy Home Programme**

The presenter based her presentation on a project done in Kibra, Githurai and Kikuyu, Kenya. She defined Home programme as an activity given by a therapist or a teacher who is working with children with disability to be done at home. She noted that most parents have challenges in implementing home programme with therapists. The research was done to enlighten professionals on how to support parents who are doing home programme.

She noted that management of disability is a full-time engagement and parents are expected to wear many hats; a teacher, therapist, nurse and doctor to this child. Parents are supposed to help their children and they need support from professionals.

#### **Results and Lessons Learnt**

- There is need to develop documents explaining challenges parents face when they are doing home programme to ensure effectiveness.
- There has been no research in Africa on intervention which is very crucial.

#### **Methodology**

The research was descriptive, cross-sectional quantitative type and the study was responded by 21 people out of 70 constituting to 30% of the total population. A guided interview questionnaire was used. Purposive sampling was done whereby parents who were coming for therapy already implementing home programme were targeted. Study site: study included The Njeri Maria Foundation' (NMF) located in Kikuyu and 'Ujiachilie' located at the St. Joseph Catholic Church, Kahawa Wendani, both in Kiambu county.

#### **Presentation Findings**

- The ability to perform three activities received from therapist means, they had a large number of activities to undertake and from the results, most parents had problem with implementation.

- Some lacked equipment and could assist, two respondents said they were new and they were still trying to understand what it's all about.
- Lack of hand-outs was also a challenge.
- In terms of time allocation, most of them took three to four days a week to do the activities, meaning they embrace it and this was a positive response.

## **Conclusions**

Parents experience barriers in implementation of home programme:

- Lack of suitable equipment at home.
- Limited time due to other household responsibilities.
- Lack of knowledge
- Inadequate therapist support.
- Lack of hand-outs for reference.
- Minimum assistance at home to undertake some of the activities given.

## **Presentation Recommendations**

To help support parents and caregivers in the implementation of home program, following recommendations can be put in place:

- Adapting low cost or available resources to use as equipment.
- Training caregivers on specific home program
- Monitoring of home program
- Provision of handouts for reference
- Consideration of home environment when prescribing home program.
- Successful OTHP require collaboration
- Training caregivers to incorporate OTHP in daily routine.
- Recommendation of adaptive home utilities as equipment.
- An establishment of structures in home program is important (clear stakeholder, guidelines).
- A research to be done from other settings.

## **Questions and Answers**

**Question:** Where is the source of handouts when you go for visitation because, the government only sends capitation to the children who are in school and not the home-based children?

**Answer:** Handouts are provided by our organization for parents depending on different disabilities of children. We have those with rickets, CP and autism. I would urge other institutions to develop handouts that are specifically for parents.



## **Benefits of Parental Involvement in Educational Interventions for Learners with Disabilities in England: Teachers' Perspectives**

In their presentation, the presenters noted that parental involvement in education of their children is beneficial particularly for those with disabilities. Education intervention happens in any education context or any school context because there will always be children who would not learn at speed as other children. The aim of the paper was to examine primary and secondary teachers' perspective on the benefits of parental involvement in educational interventions for learners with disabilities.

### **Presentation Findings**

- They noted the need for schools and parents to work together in establishing the aims of parent participation. This will help mark progress and build trust because lack of parental involvement may affect student outcomes.
- Another important context is that it is generally accepted that without the positive cooperation between family and school, it is not possible to reach the high demands for educational outcomes by a demanding society.
- Some parents may need some extra help. Teachers and schools can provide training like home-based support. For example, completing homework and other schoolwork.
- There are some challenges for parental involvement and for teachers which include; time constraints, dealing with large number of student and language and cultural barrier to parents. (Based on England and UK contextual system). Poor parenting is sometimes rated according to parents-teacher's perspective.
- Child care is a challenge because parents sometimes may have other children leading to child care issues. In England, children and families ACT 2014 (DfE, 2015) has given a lot of power to parents. Parents have specific rights of participation in their children's schooling through code of practice. There is a clause which states that parent involvement is very crucial.
- Practice: there is an expectation in the code of practice that organisations working with families with SEND, to have early and structured discussions to allow them understand the pupil's areas of strength and difficulties and parent's concerns. The agreed outcomes sought for the child in identifying the next step. Parents should be informed of all information and record taken.
- At school level, parents are commonly involved in all stages of the SEND processes from identification of needs, planning for intervention, statutory assessment and providing the right provision. This means pupils learning needs and school structures must be adopted and critically discussed with parents. They are expected to present views of their children with special needs.
- Schools should help teachers to support parents and enable them to be effective co-educators by providing the right training.
- Support parents who face barriers to getting involved suggesting and re-assessing the school's culture.

- Schools should develop policy, provision and practice that facilitate teacher-parent relations for improved partnership and collaboration.

### **Influence of Parental Engagement in Planning of Transition of Learners with Disabilities in Integrated Primary Schools in Thika Sub-County, Kenya**

The presenter defined transition in schooling terms, as a process of moving from one educational setting to another. For a smooth transition to be achieved in the curriculum, parents and caregivers must be involved. This is because, they understand the learners better. They know them from the initial stages of development and their abilities as well. Transition to integrated school has been a challenge and we would like to see engagement of the parents or involvement of these parent in the transition.

The objective of the study was to assess the influence of parental engagement in the transition of learners with disabilities in integrated schools in Kiambu county specifically Thika sub-county.

#### **Presentation Findings**

- 17.2% of the special needs teachers strongly agreed with the view that parents are not required to provide instructional materials to enable smooth transition of learners with disabilities to integrated schools.
- 3.8% of the teachers strongly agreed that, to improve transition of learners with disabilities to integrated schools, parents attend meetings with school stakeholders on how to facilitate transition of learners with disabilities.
- 20.7% of the teachers strongly agreed that, on many occasions, parents are involved in allocating resources to specific activities which involve transition of learners with disabilities.
- However, majority of the special needs teachers strongly agreed that parents are often involved when finances are required to provide facilities for learners with disabilities depending on their conditions.
- Respondents agree with the fact that the role of parents in planning for transition of learners with disabilities is important and thus should not be neglected.

#### **Conclusion**

These findings affirm the fact that parents constitute a key pillar in the planning for transition of learners with disabilities to schools.

**Question:** Seems your research is based on parents who can access the internet and materials for information. Please clarify on marginalized areas where culture is an issue and how it treats people with disabilities.

**Answer:** There is no country where people with disabilities have been fully accepted whether in schools and spiritual spaces.

**Question:** What do we advise the government on poor integration and lack of equipment in these schools?

### **Outcomes of Parents' Engagement in Assessment and Intervention for Learners with Disabilities: An Inclusive Education Perspective from Isiolo and Laikipia Counties, Kenya.**

The presentation was based on the project they implemented in Laikipia and Isiolo. It is an inclusive perspective and is based on the effect of parental engagement, assessment and intervention for learners with disabilities. The main purpose of the project was to improve learning outcomes and life opportunities for 1,200 marginalized children with disabilities within those two counties.

#### **Main Result Areas**

- Parents & Communities engagement in education and protection of marginalized children with disabilities
- Improvement on quality of teaching and learning
- Effectiveness in implementation of IE policies at county and national level
- Improvement on access to inclusive quality education

The project was rolled out in the year 2021. Washington project tool was used in preliminary disability screening.

#### **Findings/Outcomes**

##### **Immediate Results During and after Interventions**

- 1,222 CWD from 40 schools were reached with services including educational support-learning materials for both school and home.
- 12 children were re-integrated back to school
- Over 10,000 persons from 7 communities across Laikipia and Isiolo Counties were sensitized on disability and child protection
- 3000 persons were provided with Food at home through Humanitarian interventions
- Sensitization and life skills training through child-to-child was done in 40 clubs
- 257 CWDs were reached through Home based Learning
- 146 parents improved and strengthened their care experience and wellbeing for CWD through Quarterly Parent Support Group Meetings

##### **Child Level Outcomes**

- Children improved their capabilities to move, sit, walk, attend school, socialize and protect themselves

- Acceptance and belonging within their communities
- Improved access to services and support such as assistive devices, medical and education
- Improved learning outcomes among learners with disabilities
- Improved in physical, intellectual/cognitive capabilities (Communication and attention) through playing, singing, dancing, colouring, joining dots and counting
- Reduced anxiety and stress among children and improved self esteem
- Improved Health, self-care and some have transited to school through home-learning.

### **Parental Level Outcomes**

- Parents improved standards of living, income and access to basic services for CWD
- Increased Parental time with their children
- Improved access to social services by households hence increased quality of life
- Better coping strategies by families through support systems established

### **Community Level Outcomes**

- Improved attitude and practice towards disability.
- Community members have taken their role as agents of change in sensitization on disability and protection against child abuse.
- School communities have gained better understanding on life skills, social inclusion and their rights, which has been seen to impart discipline at school. This has reduced drop-outs and built confidence among learners thus improving participation in learning.
- Improved economic standards for families hence directly impacting education, health and general well-being of children with disabilities in the communities.

### **Lessons Learnt**

- Alignment to government policies, Programmes and structures generated commitment and support.
- Equipping parents with knowledge and skills in disability effectively cascades the burden of care from institutions to households while ensuring quality and improved access to education outcomes for CWD
- Strengthening parental and household centred capacities in care harnesses more resources for community-based care and championing for the rights of parents and CWD
- Empowering parents on Home-Based care enables them to transfer capabilities to CWD and leads to improved self-care and transition to advanced capabilities for CWDs.
- Providing support for regular parental engagement and meetings leads to improved care experiences and wellbeing for CWDs. This leads to reduced stigma and exchange of learning on care and linkages.
- Integrating parental support with humanitarian, peace building and prevention of disabilities helps sustain the resilience in care for CWD.

## **Recommendations**

- There is need for actors to embrace an integrated approach to programming in implementing inclusive education projects by utilising interventions that touch on child's socio-emotional, psychosocial, economic, academic and cognitive well-being.
- A multi-sectoral approach to inclusive education and early intervention programs is crucial in achieving high impact from interventions; collaborating and working in synergy across different sectors like the Ministry of Health, social services, Children's services and the National Council for persons with Disabilities.
- Employing Parent and caregiver Centred-approaches is effective in increasing access to services while improving education, safety and protection outcomes for Children with Disabilities
- Actors in Education programming should enhance Social Inclusion awareness in driving change at the school and community level. When well utilized it significantly contributes to positive behavioural and attitudinal changes toward disability and promotes participation of Children with Disabilities in Education.
- The government and specifically the MoE ought to provide clear implementation strategies for home-based learning since it's a key approach in addressing learning needs of children under home based care.

## **Questions**

**Question:** Is the stem cell treatment that is being done in India available in Kenya?

**Answer:** It is not available locally. There is no evidence that stem cell treatment has enabled any child to actually become less disabled and autism does not disappear.

## **Comments**

- The chairman for KISE Pre-primary School informed all participants about a model school in KISE that is inclusive and admissions are open for next year. He called upon parents to register their children in the institution.

- Parents have gone through a lot when buying drugs, sometimes learners are out of school because of hospital issues. There is need for a policy on this issue.

- A person living with dyslexia informed participants that "It has been a tough journey for me. Going through school where nobody understands you including teachers but my mother's support kept me going. I was later assessed by KISE that's why am so happy to be here again. They recommended I join a special needs school."

He has an organization called the dyslexia community ability and has a you tube channel where he creates awareness through with activities like golf and visiting schools. Parents should engage with other children with special need and not limit to their own

- A representative from the President awards Kenya gave an assurance that they will come up with a way to assist young people with disabilities and special needs. They will also find a way to ease pressure on the teachers and parents to make sure that these children get the best.

## **Panel 2: Parents Role in Assessment and Interventions for Learners with Disabilities**

### **Parents Support: A Key Factor in Maximizing Success in Assessment and Intervention for Children with Intellectual Disability within Siaya County, Kenya**

#### **Introduction**

Intellectual disability assessment can assist in determining the learning potential or intellectual ability of a person (a child for this matter), and therefore plays a vital role in special education. Parents can play active roles in helping with the assessment of children with intellectual disabilities because they understand their children more than anyone else, and can share information on their behalf whenever they are not in a position to, as well as helping the children to cooperate with the assessor.

#### **Methodology**

This study was a survey conducted in homes and schools of CWIDs within Siaya County, and the targeted respondents were parents of CWIDs, teachers and caregivers supporting learners with IDs. All ethical considerations in research were adhered to protect the rights of the participants, enhance the validity of the research and maintain scientific integrity.

#### **Findings from Parents and Home Caregivers**

- Out of the 135 parents and home caregivers, 17% find it convenient to stay with the children with intellectual disability, while 83% do not.
- All parents and caregivers who are aware of the signs of a child with intellectual disability.
- Out of the 135 respondents, 94.1% have heard about EARCs, while 8 (5.9%) have not.
- A total of 76.3% have taken part in the assessment process of a child at the EARC, while 23.7% have not.

#### **Findings from Teachers and School Caregivers**

- All respondents confirmed that their learners have placement letters from the EARC.
- All teachers and caregivers in schools confirmed that they involve parents in affairs of their children.
- Participants indicated that parents are involved in assessment of their children.

#### **Findings from Assessors**

- All assessors indicated that assessment process requires the presence of a parent to give historical background of the disability, to help the child communicate and to prepare the child for assessment.
- All assessors reported that parents are responsible for their children after assessment in implementing the assessor's recommendations and preparing the child for subsequent assessments.
- All assessors agreed that parental involvement in educational development of children with ID is important and that they can advocate for their children's rights.

- All the 14 assessors also agreed that parents can be used in advocacy roles about children with ID.

### **Conclusion and Recommendations**

- Parents of children with ID in Siaya County are generally positive in supporting their children when it comes to assessment and they ensure maximum intervention for their children.
- Parents play a key role in ensuring that CWID get assessed as they willfully take them to EARCs and participate during assessment process. They also support intervention programs.
- The Ministry of Education should conduct short training sessions for parents of children with ID to increase awareness and support skills. This will empower and make them effective collaborators in the lifelong learning of their children.
- Studies should be conducted in other counties in Kenya so as to understand how parents are involved in assessment and intervention for children with ID.

### **Misdiagnosis and its Effects on the Lives of Parents and School System: A Case Study of Mauritius**

#### **Background and Objectives**

Having a child implies major responsibilities, another set of worries and decision making regarding the future of the latter. Parents having a child with special needs need to be more involved and engaged in the life of their child in many ways. From nurturing to negotiating, parents rely on diagnosis of professionals to face challenges and obstacles of living with a child having special needs. This paper was about the effects of misdiagnosis of a child with special educational needs on parents. The case study was about a 5-year-old who was misdiagnosed with autism by a group of professionals in Mauritius.

#### **Methodology**

A qualitative research method was opted for the case study. The parents came forward with a request to extend the child's stay in a private pre-school. An Individual Educational Plan (IEP) was developed, and the child was observed as his progress was being monitored. Parents of the child who was misdiagnosed were interviewed. The data collected was transcribed to understand their living experiences and the effect of having a misdiagnosed child.

#### **Findings**

- Results showed that parents underwent high level of stress and tried to adjust to the initial report of the diagnosis.
- Parents were living in a denial phase of accepting the fact that their child was autistic.
- The drift from a happy child to a reserved and visibly abnormal behaviours, put parents in very difficult situations.
- Contribution of parents during diagnostic and assessment of their child is highly important.

- Due to misdiagnosis, the preschool manager responded negatively about the child and recommended in advance that the child be sent to a special school instead of staying one more year in the preschool setting.

### **Recommendations**

- Parental collaboration and involvement during assessment or diagnosis is key.
- Thorough interview be carried out to identify background of the child, profiling of the child should be created to re-align with present situation.

## **Parental Involvement in Identification of Disability, Functional Assessment and Intervention: Informing Policy and Practice in Kenya**

### **Introduction**

Factors that influence educational outcomes for children with disabilities include early identification assessment and intervention. The two most critical factors of greatest impact to meaningful participation in education around the world are identified as family's socio-economic & cultural status and parental involvement in children. It is important that teachers and policy makers are aware of these factors in order to facilitate provision of supportive parental engagement to enhance the child's well-being.

### **Policy and legislation on early functional assessment and intervention**

The Totally Integrated Quality Education and Training Committee report of 2005 emphasized early intervention for children with special needs in education, improving accessibility, equity, relevance and quality with special attention to gender sensitivity, the disabled and disadvantaged. The sector policy for learners and trainees with disabilities (2018) also emphasizes parental involvement as a key component of service provision for learners and trainees with disabilities.

The National Education Sector Strategic Plan (NESSP, 2018-2022) advances the argument that learners whose parents consult with teachers regularly achieve better results than those whose parents do not take time to meet with educators.

### **Parental Involvement**

- Parents are the earliest facilitators of intervention for children with disabilities.
- Parental involvement in child development activities positively influences not only achievements in child development, but also future prospects, social relationships and mental conditions.
- Parental involvement in a child's education has greater impact on learning than variables such as social class, level of parental education or parental income.
- Some of the ways that parents get involved in issues related to their children with disabilities include parenting, volunteering in schools, supporting learning and development at home and collaborating with the community.



- Parenting should include play as a key responsibility in child rearing, which is usually not the case in many instances.
- Parental involvement at home reinforces institution-based learning, including educational enrichment activities.
- The sector policy recognizes home-based interventions as part of the continuum of provisions.
- Benefits of parental involvement in education have been seen to be strongest for younger children.
- Factors related to culture, levels of literacy in parents and poverty minimize parental involvement in early assessment & intervention.
- Where parental involvement is unsatisfactory, children could be said to be underrepresented as parents make decisions for them.
- Parent's organizations encourage parents to be involved.

### **Variables and Challenges Facing Parental Involvement**

- Family's beliefs and aspirations around education.
- Culture e.g. parents hiding children with disabilities
- Policy and legislation.
- Healthy relationships. When parents feel that their involvement is not valued, they are less likely to get involved.
- Parental self-efficacy and education levels.
- Parents' own experiences.
- Socio-economic status of the family.
- Expectations by teachers.
- Gender: mothers tend to be more involved in the affairs of their children than fathers.
- When teachers are not predisposed to listen, barriers to positive parental involvement can develop.

### **Possible theoretical Frameworks to inform the framework for Parental Involvement**

- Bronfenbrenner's Bio-ecological model can be applied to investigate and understand the relationship between the child, their family, institutions involved in functional assessment and the community.
- Bandura's social cognitive/self-efficacy theory appears appropriate to establish the levels of confidence in parents, factors influencing their involvement and give them self-confidence.

### **Conclusion and Way Forward**

- Professionals should ensure that parents understand expectations
- Policies and practices should be well explained.
- Schools and assessment centres should also be aware of and work towards a balance in power relations.
- Parental involvement should be valued.
- Communication with parents should be well planned and clear.

- Teachers should be more responsive in order to increase parental involvement.
- Two-way communication is key to nurture parental involvement.

### **The Role of Parents in Assessment and Interventions for Learners with Disabilities**

Access to interventions for children with disability and more so those with ‘intellectual disability’ has been traditional for a very long time. With the changing world, the role of artificial intelligence and use of biomarkers has not been explored on how it improves this experience and process. This study explored the role of parents in assessment and interventions.

#### **Objectives**

The purpose of this study was to review the role of parents, caregivers and therapists in Kenya whose children use Artificial Intelligence and biomarkers to design and apply technology and human approach to assessment and application of therapeutics.

#### **Methodology**

This study adopted use of interviews and experiences, impact stories and reviewed reports to provide the qualitative and quantitative data that was analyzed and reported. The outcome was presented using a narrative format. Respondents were parents of learners with disability in Nairobi. The exclusion criteria applied was that the parent was participating in the interventions process as provided by the biomarkers and AI platform Izola by Vitafluence. They were members of the parents’ network *Through the Roof* as well as fulltime and active parents of a child with disability.

#### **Outcomes/Lessons Learnt**

- Application of AI and biomarkers to design and apply therapeutics was found to be more accurate in matching therapeutic needs to the design of therapy to be applied. Use of AI also made the plan clear with no guess work to application and resources to use.
- Most participants indicated that the use of AI introduced appropriate technological use in advancing and meeting therapy needs of children making their achievements of activities of daily living and their independence.
- Parents often feel overwhelmed by the professionals who ignore them in the process and also do not include them leading to termination of process or dissatisfaction and mistrust of the professionals.
- 96% of respondents indicated that their assessors ignored them when it came to the assessment process.
- Children whose parents were fully involved in their assessment as well as implementing interventions had a higher developmental growth quotient. The interventions worked better for their children as compared to those whose parents did not play a role. These learners had more confidence than those whose parents did not play a role in their lives.
- Parents who opted for AI and biomarkers for their therapeutics journey had a constant presence in the interventions journey of their child.

## **Recommendations**

- Parents need to be well-versed in all laws governing a child with disability from wrong interventions, experimentation and abuse by professionals.
- Parents and guardians should be prepared to offer insight into whether current strategies and instruction right from assessment to interventions are helping children with disability. They should also participate issues such as learning and provide suggestions for change and improvement.
- Parents and caregivers should not be intimidated by the personnel and professionals in the institutions that carry out the assessment and interventions for their learners with disability.
- Parents should strive to attend all assessments, interventions and meetings to ensure participation in decision-making, implementation of processes and to provide input on all aspects of their children's assessment and interventions.
- Parents to form support groups.
- Government agencies, religious bodies and family networks to join hands in finding solutions to the gaps in supporting parents fulfil their role as key members of the assessment and intervention teams for the learners with disability.
- Parents to:
  - ✓ Communicate with all professionals interacting with their children with disability in writing whenever possible, and maintain these communications for future reference.
  - ✓ Keep records of a child's assessment and interventions.
  - ✓ Learn about disability in order to support their children.

The presenter congratulated parents of children with special needs and disabilities for the support they are giving their children. He expressed honour, respect and love to parents some of whom have been divorced because of children with disability.

The presenter highlighted benefits for persons with disability in this country; some of them include tax exemption, importation of tax-free vehicles and preferential treatment in terms of job opportunity and access to government procurement opportunities. He implored that this should also be extended to parents with children with severe disabilities.

## **Guest: Executive Director/CEO at National Council for Persons with Disabilities (NCPWD)**

The CEO NCPWD acknowledged that parents of children with disabilities go through tough times. Some mothers go through tough times but despite this come out strongly with initiatives that define how disability and access to opportunities for children with disabilities are addressed.

## **Highlights**

- Many changes in this country and beyond in one way or the other were initiated by parents of children with disabilities.

- All the teachers undertaking teacher training whether in universities or colleges should also be obligated to go through special needs education training at KISE before they are employed by TSC. Just like lawyers must go through Kenya school of law before they practice. Otherwise, the country will continue pushing the perspective of education through exclusion, stigma, labelling and stereotypes.
- In relation to CBC and learners with disabilities, the CEO expressed that they have put forward the issue on capitation of learners with disabilities and there should be no ranking of learners with disabilities.

### **Key Note Speaker: Judge of the Court of Appeal**

The justice quoted William Arthur; *“A true friend knows your weakness but shows you your strength, feels your feelings but fortifies your faith, sees your anxieties but frees your spirit.”* He noted that children with disabilities have opportunities ahead of them. Thus, parental engagement and advocacy ensures that they nature potential of their children. This has to begin from somewhere. Where should this journey begin? It begins with the onset of disability. For some it begins at birth and others much later in life amid other children who do not have special needs and disabilities, but all are our children.

### **Highlights**

- He pointed out the need for parents to familiarize themselves with international treaties that are the foundation of rights, the constitution, policies and laws for persons with disabilities. He advocated for institutions to join hands so that they can be able to fight for rights of children with disabilities.
- He cautioned parents to never focus on the weakness of their children unless it is clearly intended for the purpose of intervention. Some parents hide their children because of hopelessness and despair. They should not be blamed because they do not know whether to look after their children or go to work. They may have no information or idea on where to seek help.
- Beginning of better days ahead entails parents knowing the strength and needs of their children and how to navigate through life. This can be supported through networking, partnerships and sharing ideas. Thus, information sharing becomes critical.
- Mentorship plays a significant role in educating learners with disabilities.
- The biggest disability anyone can face is attitude. He informed participants that he had two occasions of discrimination on job offers in senior government positions because of the attitude people have towards persons with visual disabilities. He was once put on the list of lawyers to be appointed as judge of the high court. The list was taken to the then minister for justice to present to president for appointment, and the minister declined act on grounds of blindness.
- Kenyans value persons with disabilities who are able to prove their worth, competencies and potential. He urged relatives to support learners with disabilities to prove their worth because we have persons with disabilities who have excelled. Some are university lecturers

and senior public officers, while others are in the international spheres doing great jobs, notwithstanding their disability.

- He cautioned parents of learners with disabilities against considering their children as patients and dumping them in medical, charitable institutions and boarding schools.
- He stressed that disability should be a norm among every one of us hence, it would be offensive talking about ‘normal people’, as no one is normal or abnormal. “We are not disabled by our disabilities, those are just limitations thrown on our way by circumstances”.
- He cautioned against institutionalization of persons with disability with exception of severe disabilities where attention is needed for 24 hours. He emphasized that home is where everyone must be whether one is well or unwell and whether with special needs or not.
- Parents of children with disabilities must be at the forefront and invest in adaptive and assistive technology. However, he noted that electronic assistive devices are expensive and most parents may not be able to afford them.
- In sports, some children with disability are excluded because activities are not tailored to enable them enjoy recreation.
- He encouraged parents to take responsibility of identifying support programmes, intervention programmes and institutions that can shape their children’s talents and provide them with exposure and the necessary opportunity.
- Parents should familiarize themselves with very basic laws and freedom rights, such as: The Persons with Disability Act, the Constitution of Kenya, specifically articles on equality and discrimination, the Basic Education Act and Employment Act among others.
- Parents and teachers to be sensitized on the right to privacy for children with disabilities.
- It will be noble to advocate for affirmative action so that those left behind because of prejudices, are able to come back and hold hands together and achieve. What really matters in life one’s ability.
- He advised parents to register their children with the national council for persons with disability. It is also important to advise adults with disability to carry their disability identification cards to avoid brutality from law enforcers.

## **Plenary Session 2**

### **Keynote Speaker Founding chairman of Deaf CBO in Mombasa**

The presenter is a parent to a child with hearing impairment. He is the founding chairman of Deaf CBO in Mombasa and also a board member representing special schools. His daughter lost the hearing ability due to a long illness. She got a lot of support and treatment at Coast General Hospital. She was rejected by many regular schools she could not fit in as they said. That is when he decided to advocate for other children with disability on voluntary basis through social media and Network of the NCPWD officers at county level in Mombasa and Kilifi Counties.

### **Presentation Highlights**

- He encouraged parents to take their children with disabilities to school as it is an equalizer of opportunities and skills. Children are gifted differently and they need to be nurtured, like in Music.
- He urged the government to ensure that the school curriculum is inclusive.
- Parents should be included in round-table conversations that advocate for inclusion.

### **Comments**

- NCPWD has been working with KISE to train staff from different sectors such as medical practitioners, officers of the law, Huduma Centre attendants and others in Kenyan sign language. Therefore, with time almost all sectors will have persons who can communicate effectively with the deaf.
- Schools need to have trainee and learner support assistants. KISE provides this training.
- There is a challenge of transport to facilitate movement of children from one point to another such as home to therapy centres.
- KISE is in the process of developing a state-of-the-art sports complex for a wide variety of games for persons with disabilities.
- There is need to involve parents from the grassroot level to present issues of children with disability through the counties to the national level.
- Participants were informed about the existence of a parents' association 'Through the Roof Network' which parents can join since it has ears of the National Council.

### **Plenary Roundtable: Awareness and Advocacy on Rights of Learners with Disabilities, Community Involvement in Inclusion of Learners with Disabilities and Parenting of Children with Special Needs and Disabilities, Experiences and Challenges.**

**Moderator:** She informed participants that she is a parent to a child with special needs (dyslexia). She had a challenge of enrolling her child in school. However, after functional assessment in KISE, she enrolled the child at a school in Westlands and now making progress.

**Parent 1:** Is a parent to 3 children and 2 of them in the Autism spectrum through a diagnosis. "I stumbled onto a group and shared my story. Thereafter, I met two other parents who took me through and gave me awareness and their experiences calmed me down".

**Parent 2:** She reported that when her child first got diagnosed at 2 to 3yrs, she was advised to take him for speech therapy. "From my end, I couldn't find anything wrong with my child. Later in life when he turned 5 years, I came across an educational psychologist who made me understand what my child was going through. Eventually, we got a lengthy diagnosis that brought understanding and it was easier to reach out to other parents with autistic children".

**Parent 3:** Is a parent to two children with Autism, Schizophrenia and Dyslexia. "Being a first-time parent 20yrs ago, it was really difficult because there was so much stigma and accusations

of witchcraft even from religious quarters. We came up with an organization to create awareness in my community back in the village as children with disabilities are still hidden”.

**Question:** *How do you handle moments when you feel overwhelmed as a parent?*

**Parent 4:** “I started an organization that offers a support platform for parents with kids with disabilities and rare diseases to walk the journey with parents and refer each other to doctors. I would advise parents to get support from people who understand what you are going through”.

**Question:** What can our children expect with the transition from primary, secondary to tertiary institutions?

**Participant:** “We receive students according to the university entry requirements who come to study Special Education. In addition, they take two extra teaching subjects because of learner support when they are in the integrated schools. We assess students on a personal level to ascertain their capabilities at different levels so that learners in schools can get top notch services”.

**Participant:** “Special schools are well established in this country and they are spread out. The challenge is lack of adequate funding. Parents should enrol their children with disabilities in special schools as the government trains specific SNE teachers for these schools. Allow teachers to teach and mentor these children. There are still passionate teachers within us. Learners get friends and company in school from peers”.

She advised parents to allow children to do things for themselves so that they are not dependent on others for everything, but instead correct them when they go wrong. Parents should strive to support their children as much as they can when it comes to taking them to school and providing support not always waiting for lobby groups or ‘*serikali saidia*’ common phrase”.

**Presenter:** “Advocacy for inclusion begins by requesting Head teachers to be inclusive. We don’t want special schools because; they have been an excuse by parents who would rather have nothing to do with their child, but dump them in these institutions. We have special schools with students of up to 40yrs because someone took them there and never picked them up from the institution”.

Parents were urged to take their children to the nearest school as there are trained teachers. This will be made possible by making sure everybody trained by KISE is employed in high school and primary school. There is need for all schools to be well equipped to accommodate children with special needs and disability thus eliminate stigma and allow children to grow together. This will encourage seamless transition in future.

**Presenter:** “My children have intellectual disabilities of sorts; the 1<sup>st</sup> one is 15yrs old and has hit her educational ceiling as no one would take her in to any school at that age, she needs to

grow with her peers. All TVET institutions take students above 18yrs and my daughter cannot be admitted. My child cannot fit into society as we speak, if I don't have the privilege of getting things for her to do. For example, getting a teacher to come home or taking her to places to do the things she is specifically interested in. I am home schooling because I don't have any other choice”.

**Participant:** “Skill empowerment is a solution especially in an environment that is disability inclusive. Children need to be given opportunities after their training to get jobs to bridge the barrier from the conventional educational targets. Some of our children have intellectual disabilities but they can be trained. I am advocating for the space to be widened. For example, my son is able to fry an egg at the age of 23 years and that's quite a milestone; that's because, he got an opportunity to attend cooking classes”.

### **Presentation Recommendations**

- On transition; the government should ensure that employers are sensitized about tax rebates to achieve disability inclusion in employment.
- There is need to moderate fees charged by private schools.
- KICD needs to adapt a curriculum for technical institutions as is with primary and secondary education.

### **Panel 3: Support for Parents and Caregivers of Learners with Disabilities**

#### **Becoming Positive in a Negative Situation: An Exploratory Study of Psychological Wellbeing of Parents Having Children with Special Needs**

##### **Introduction**

The study was on psychological wellbeing of parents of children with special needs. It explored the struggles of being neglected in championing their children's rights and experiences of parenting.

##### **Objectives**

To investigate how having children with special needs can enable parents construct their own psychological wellbeing.

##### **Methodology**

The study used qualitative research approach and purposive sampling technique. The respondents comprised of parents of children with special needs and members of NGOs. Data was collected using semi structured interviews, Focus Group Discussions and Ryff's Psychological wellbeing tool.

##### **Findings**

- Parents of children with special needs focused primarily on the negative and found nothing positive about their situations.



- The respondents reported that they experienced hopelessness, despair, frustration, tension, anxiety and stress whenever they compared themselves to others.
- During FGDs, there was a change in their attitude and behaviour towards answering questions evidenced by acceptance of situation and giving suggestions on how to go about their situation.
- The respondents embraced planning and sticking to routine and made time out for self-care, as well as engaging in activities together with the child and other family members. More so they invested in resources and tools to help the child.
- The respondents all agreed that there is always a way out.

### **Recommendations**

- Parents need to speak out their minds to pour out what is in their hearts,
- Seek guidance and support from NGOs and private therapists.
- Maintain good relationship with caregivers, teachers and support groups,
- Parents should embrace group therapy.

### **Questions**

**Question:** What is your take on parental shaming and societal expectations?

**Answer:** When such goes on, remember you are not the problem as a parent. Always remember that you are a super parent and you know your children's capabilities and weaknesses.

**Question:** What advise can you give parents who have been left by their partners due to the birth of a special child?

**Answer:** Many parents are not willing to take responsibilities and came to each other's lives for a particular reason and since it does not fit their expectations anymore, they end up leaving. However, be positive about life and move on.

### **Disability Parenting**

#### **Introduction**

The presenter is the founder of Step by Stones NGO and a parent to two girls with different rare conditions. She has been taking care of her children for the last 16 years. She narrated that since the girls have two different conditions they could not fit in the available convectional special school settings. Step by Stones NGO was initiated to provide a support platform for parents of children with disability with an objective of improving emotional support and psychosocial welfare.

#### **Organizational strategy**

The organization conducts workshops for training caregivers on different topics, provides resources, educates parents on different areas of their children's disability and runs an online support group.

### **Lessons Learnt**

In most cases, the focus is on the child with disability and not caregiver. There is lack of information on the disability needs and support groups are key as the world is a global village.

### **Recommendations**

- Give equal attention to children with disabilities and their caregivers.
- Focus on psychosocial empowerment of parents
- Provide training manual for caregivers
- Tax exemption for parents of children with disabilities

## **Empowerment, Engagement and Support of Parents and Caregivers Through the use of Cole's Seven Step Format**

### **Introduction**

There are times the best placed person to support a parent or individual with disability may not be available. Some Occupational Therapists, have little knowledge on mental health and psychosocial support. Based on this, Njeri Maria Foundation was inspired to research on empowerment, engagement and support of parents and caregivers. The study notes that disability influences the quality of life and wellbeing of the affected persons and their families and social support is the most vital of all protective psychosocial resources. The Occupational Therapy focused on a group leadership structure (Cole's Seven Steps).

### **Cole's Seven Steps**

The Cole's Seven Steps Format is a Group-based therapy. It has a leadership structure that gives the directions on how to conduct group therapy. It can be used even in a rural setting to create a safe space and run the therapy sessions seamlessly. People have safe spaces but with no structure and hence do not meet the desired output. The 7 steps entail:

1. Introduction: Parents come in and introduce themselves, the name of the child and the session begins.
2. Activity: The activity can be as simple as people making puzzles, working together or even more complex as parents may want to know about the conditions and how to do home programs.
3. Sharing: Parents are required to share their experiences.
4. Processing: Parents come together to share their feelings as to what they relate to with the activity.
5. Generalization: The group leader picks any main points that stand out.
6. Application: They identify where they can apply the activity in their lives as they learn from each other.
7. Summary: This is for members to reflect on the activity and share what they learnt.

## **Methodology**

A needs assessment was conducted on a group of caregivers and parents bringing their children to one of the Special Education Professionals (SEP) projects and thereafter, Cole's Seven Steps format was used to conduct eight group sessions.

## **Findings**

The needs assessment highlighted structural gaps in ongoing group sessions. The caregivers and parents had a limited range of coping mechanisms, 100% of the participants shared that praying and reading the Bible were what they did to cope. Implementation of the group design based on Cole's Seven Step format and the needs assessment increased the variety of the coping mechanisms in the participants. In the sessions, the caregivers and parents were empowered to be assertive, and positive and they gained a better sense of their identity.

## **Conclusion**

- Use of structured group design based on Cole's Seven Step format was beneficial to parents and children with disabilities.
- Implementation of the Cole's Seven Step format on group intervention produced tangible impact on caregiver's experience within a duration of eight session.

## **Supporting Families of Young Children with Developmental Disabilities in Kenya: Lessons from WHO Caregivers' Skills Training Programme**

This presentation was based on a research done by the Institute for Human Development, Aga Khan University. The research mainly targeted caregivers of children with developmental disabilities. This work was on behalf of a consortium of partners: KEMRI, Wellcome Trust, APHRC, Ethiopian University, Kings College London and the WHO.

## **Background**

- Globally there are:
  - ✓ More than 53 million children with developmental disabilities (DD)
  - ✓ More than 95% live in low and middle-income countries including Africa
  - ✓ More than 50% communication and behaviour-related problems
- Existing interventions: largely from Western setting, time intensive, may require specialist
- 2017 piloting was done in Kenya and Ethiopia on the WHO Caregivers Skills Training (CST) evaluating acceptability & feasibility

## **The WHO CST Programme Overview**

- It was delivered by trained and non-specialist e.g. *community-based workers, nurses, peer caregivers*
- There were 9 group sessions and 3 home visits in 12 weeks
- Covered diverse topics and learning techniques

## **What was done**

### *Adapting the Caregiver Skills Training Programme*

This was led by a team of researchers and clinicians at the KEMRI-Wellcome Trust Programme (Kilifi) and the APHRC (Nairobi). They first conducted an extensive consultation and review asking caregivers and other stakeholders their views on the draft CST materials, potential barriers and implementation of a caregiver-based intervention in rural and urban informal settlements in Kenya.

Based on the feedback, materials were adapted to fit in the Kenyan context and then translated to Kiswahili. Facilitators of the program (research assistants, clinical officers and health workers) conducted competency training of the weekly CST program sessions with two groups of caregivers (literate and non-literate) in Kenya.

### **Pilot Testing**

They pilot-tested the CST program in urban and rural Kenya with a total of 80 caregivers with a child with disability.

### **Post Study Evaluation**

They organized group discussions with caregivers who took part in the CST programme to learn about their programme experiences of raising a child with disability.

### **Findings**

- The CST programme was accepted and seemed feasible to implement in different socio-cultural settings.
- There were improvements in caregiver and child outcomes as it transformed caregivers' attitudes and beliefs about their children's capabilities. Caregivers found better ways to engage their children in daily tasks.
- The caregivers who participated in the programme felt less stressed during child care. There was an improvement in their understanding of their children's communication needs, confidence in teaching peers of children with DD and enhanced knowledge on developmental disabilities.
- The 'peer-group' format was highly appreciated as it enabled caregivers learn from each other's experiences, encouraged each other and coped with life stressors.
- All the CST content was deemed relevant and relatable to real situations.

### **Ongoing work**

- The team in Kenya is currently working with the researchers in Ethiopia, Kings College London and University of Oxford. Their main objective is to develop and evaluate context-specific training packages to raise community awareness and reduce stigma against children with DD.
- The ongoing study funded by the National Institute for Health and Care Research (NIHR) will involve working collaboratively with caregivers of children with

disabilities and various stakeholders to develop a multi-sectorial care model for children and their families to improve their health, education and inclusion.

- A large trial of the CST will be undertaken to test its effectiveness.

### **Implications and Recommendations**

- It is important to prioritize activities aimed at raising awareness about developmental disabilities to decrease misconceptions and tackle stigma.
- There is need to scale up community-based support for children with DD to address the urgent needs of families, including inclusivity and responsiveness to caregivers' life situations.

## **Awareness and Advocacy on Rights of Learners with Disability**

### **Introduction**

The rights of learners with disability are enshrined and protected in the UNCRPD. More than 1 billion people or 14% of the world population are living with some form of disability. However, many are not aware of their disability and hence have no idea about their rights.

Learners with disability are disproportionately represented and they are among the worlds poorest in learning. They lack equal access to basic learning resources and appropriate learning. Parents of learners with disability must learn to effectively navigate the maze of special education processes and laws. Advocacy and awareness is carried out by mainly parents. However, they lack adequate knowledge and capacity.

### **Objectives**

The purpose of this study was to review the rights of learners with disability in Nairobi, Kenya. Specifically:

- How the rights are advocated
- Awareness of the rights
- create an awareness-raising campaign to build an understanding and tolerant community integration of learners with disability

### **Outcomes/Findings**

- 160 parents and 100 teachers were knowledgeable of at least a minimum of five rights out of the sixty rights in the UNRCPD
- Emphasis from participants on Supported learning advocacy not instructed or substituted learning process.
- Areas that need Awareness and Advocacy:
  - ✓ *Ignorance of special needs issues,*
  - ✓ *Stigma and hostility by the community,*
  - ✓ *Parental indifference in raising children with special needs,*
  - ✓ *Mass media representation,*

- ✓ *Summation of needs.*

### **Way Forward**

- There is need to develop specific issue-based advocacy programs that have parental input on their needs and those of their children with special needs.
- Gather and implement information and make decisions that promote the long-term interests of affected children with a goal of desirable outcomes from awareness and advocacy.
- Create awareness and carry out advocacy campaigns targeted at inclusion of learners with disability.
- Parents of learners with disability in the community should become the drivers of awareness and advocacy as they will be able to direct the advocacy to what's needed.
- Parents and caregivers need to:
  - ✓ Learn all about their child's disability
  - ✓ Be problem solvers not problem makers (solution provider)
  - ✓ Always avoid the blame game
  - ✓ Be a futurist and think long term
  - ✓ Get to know service providers like teachers
  - ✓ Become a master planner
- Advocacy and awareness creation should present the rights of learners with disability. The advocate should become their voice without replacing them.
- Advocates should:
  - ✓ *Continually seek to improve services for learners with disability*
  - ✓ *Encourage professionals and work with them to improve service provision*
  - ✓ *Document and objectively report availability of services to learners with disability*
  - ✓ *Monitor placements and services*
  - ✓ Follow-up and advocate for enactment of laws

### **Comments**

Parents and caregivers of children with disability should be motivated, embraced and appreciated without prejudice. Let's all work towards an inclusive society without discrimination.

A participant requested MoE for Edu Afya Insurance for learners with special needs and disabilities similar to the one for secondary school students. Medicine required by these children is quite expensive.

## **Panel 4: Parenting Children with Special Needs and Disabilities: Experiences and Challenges**

### **Parenting Children with Special Needs and Disabilities: Experiences and Challenges**

#### **Introduction**

In Kenya, the term ‘special Needs’ refers to children who have disabilities such as developmental and learning challenges without specifically presenting with obvious physical disabilities. Challenges faced by parents of children with Special Needs are exacerbated by factors such as community attitudes and cultural beliefs and institutional. More so, superstition that evil spirits, witchcraft or a mother’s improper relationships causes disabilities have resulted in women being abandoned by their husbands thus end up bearing the brunt of caring for the child with special needs alone.

#### **Objectives**

The research focused on challenges faced by parents as they parent children with learning disabilities in Kenya and examined challenges of economic, social, cultural, technological, political, legal and psychological in the parenting process.

#### **Methodology**

The study methodology entailed In-depth interviews, and thematic analysis was applied on qualitative data on a 30% sample of a population of 2000 parents.

#### **Findings**

##### **Family Impact**

80% of the respondents indicated that their family dynamics changed. The changes were mostly negative such as: divorce, single parent (being mother/father only), ostracization by extended family and community, older/younger siblings acting out, homicides, child abandonment. This was attributed to the fact that parents were still in denial, depressed and not giving attention to any other issues other than the child’s special needs.

##### **Social Impact**

A staggering 100% of the respondents indicated that the structure in society is the biggest challenge they experience. The social setup in Kenya has excluded or kept the child with special needs in isolation instead of addition of inclusive spaces for all their activities. Consequently, society has no good grasp of special needs, and when a community has no idea, it becomes hostile thus perpetuating discrimination and stigmatization.

##### **Financial Impact**

Results indicated that 72% of the respondents struggle financially and socially to get resources and material needs for their children. It also indicated that being unemployed, fulltime caregivers of their children and social discrimination negatively affected them. Another 22%

of the respondents indicated having been terminated from their professions as they were not given time off for therapy sessions and clinics. Only 12% of the respondents chose to take the financial downtime to ensure interventions were done for their children.

### **Emotional and Psychological Impact**

All the respondents indicated that they needed mental health support in terms of counselling and medication however, only 5% were under the care of a health professional while, 62% indicated that they could not afford professional mental health care. On the other hand, 70% of the respondents indicated that they did not want it known they were having mental health care issues as this will further ostracize them in society.

### **Accessibility for Special Needs Services**

Accessibility is a challenge that leaves the families isolated and unable to go places. A majority of the respondents (92%) indicated that accessibility of services was difficult and sometimes impossible. This includes inaccessibility of resources, infrastructure, government services, schools, hospitals, availability of qualified medical officers and work environments that are not inclusive.

### **Understanding and Awareness**

Results indicated that (82%) of the respondents had a vague understanding of special needs and lacked awareness of the availability of programs, services and policies that may benefit their children with special needs. All the respondents indicated that stereotypes and prejudices regarding special needs were rampant in the communities. Furthermore, it was noted that children with special needs are being raised by single parent units (mostly the mothers) who are also unemployed with less support from any external source.

### **Self-Care and Support**

Parents of children with special needs are often exhausted and frequently become depressed. It is important that they create time to relax and refuel themselves. This nature of support is often received from other parents of children with special needs.

### **Exhaustion and fatigue**

The finding showed that parents of special needs children are stressed, exhausted, fatigued and parents suffer post-traumatic stress disorder (PTSD) due to the degree of care and alertness required of them. They are on full-time alert cycle from the time of diagnosis.

### **Recommendations**

- The researchers recommend that parents be educated on policy and resources available by the policy implementers.
- Parents should try to find support groups within these specialised programmes to be able to connect with other people who are going through the same challenges.



- Awareness should be created in our schools and social places on the effects of discriminating against children with special needs as it affects both the children and their parents adversely.
- There is need for healthcare providers to educate the parents on their children's conditions, the causes and enlighten the public to mitigate societal stigmatisation and lack of awareness.
- Schools should be tasked with the duty of making children with special needs comfortable by providing accessible amenities and ensuring that other children do not discriminate against them.
- Religious leaders should be enlightened and mandated to encourage their members not to discriminate against people with special needs but rather to encourage such parents as their support goes a long way to alleviate the stress of caring for their children with special needs.

### **The Relationship among Parenting Styles, Learners' Involvement in Problem Behaviour and Academic Performance in Nairobi County, Kenya**

Parenting a child involves providing physical care, support, love and guidance for healthy development of a child. During the 18<sup>th</sup> century in the USA, the church and the state worked together to manage children's behaviour according to strict interpretation of the Bible. In the traditional African society, children belonged to the community and were well taken care of by their parents and extended family members. Everyone ensured that they were disciplined and well behaved.

#### **Objectives of the Study**

This study sought to:

1. Find out the factors that influence parenting styles in Nairobi County, Kenya.
2. Establish the influence of parenting styles on learners' involvement in problem behaviours in Nairobi County, Kenya.
3. Determine the influence of involvement in behaviour problems on learners' academic performance in Nairobi County, Kenya.
4. Find out the relationship between parenting styles and learners' academic performance in Nairobi County, Kenya.

#### **Methodology**

This research study used cross-sectional descriptive survey design involving both quantitative and qualitative methods. This study was carried out in Nairobi County, Kenya. Parents of the targeted form three students were also included in the study. Multi-stage random sampling technique was used. The main tools for this research study were questionnaires for students and an interview guide for parents.

## **Study Findings**

- A majority of parents cited: media and modern technology, dual career, tight schedules, family conflicts, divorce, daily stresses, family crises, and socio-economic factors.
- A majority of the parents reported that their children spent so much time watching television (movies), listening to the radio (music) or surfing the Internet on their mobile phones.
- A majority of parents used authoritative parenting style and less than a quarter of parents used permissive parenting style. Very few parents used either authoritarian or neglectful parenting styles.
- A majority of children with authoritative parents had never engaged in behaviour disorders while almost half of the children with permissive parents engaged in behaviour disorders.
- A majority of children with uninvolved/neglectful parents engaged in behaviour disorders compared to those of parents who used other parenting styles.
- Less than a quarter of the children reported to have engaged in various behaviour disorders: drug and substance abuse, teenage sex, student unrest, truancy, dropping out of school and aggression towards others and property.
- All behaviour disorders significantly affected children's academic performance as majority of them performed averagely and about a quarter of the children performed less than average in academics.
- Authoritative parenting was positively correlated with academic performance whereas authoritarian, permissive and uninvolved or neglectful parenting styles were found to be negatively correlated with children's academic performance.

## **Conclusions**

- A majority of parents used authoritative parenting style in bringing up their children with a few of them using permissive and authoritarian parenting styles.
- Children of authoritative parents showed fewer behaviour disorders compared to children of parents who used authoritarian, permissive and neglectful/uninvolved parenting styles.
- Authoritative parenting style was positively correlated to academic performance. Authoritarian, permissive and neglectful/uninvolved parenting styles were negatively correlated with academic performance.
- Children engaged in various behaviour disorders although majority of parents were not aware. These behaviour disorders negatively influenced academic performance.

## **Recommendations**

- MoE should formulate a policy on education of children with emotional and behaviour disorders.
- Parents should strive to know their children's whereabouts and monitor their activities as this can protect children from engaging in behaviour disorders.
- Parents should purpose and dedicate quality time to their children, dialogue with them, listen to their concerns and address them effectively.

- Parents should seek to know their children's friends, their places of residence and possibly the parents of their children's friends.
- Research could be carried out on ethnic differences in the impact of parenting styles on children's behaviour and academic performance or factors other than parenting that make children to engage in behaviour disorders.

## **The Children with Physical Disabilities' Experiences and Challenges as Parents Impact in them Positivity, Self-Confidence, "Bravity" and Hardworking for Long Life Differently Abled in Makueni and Kitui Counties Kenya.**

### **Introduction**

The expectation of a new born child is characterized by fear and uncertainty. There is great joy for parents when the midwife breaks the news of the birth of a healthy baby boy or baby girl. Parents wish that the child would live and grow whatever their conditions. One parent who gave birth to a child without limbs (Phocomelia condition) was quoted saying, "God, I wish my son should live; I won't mind carrying him the rest of my life, taking him out of the house to sunbathe and returning him to the house".

This study sought to investigate experiences of children with physical disability and challenges that parent face as they impart positivity, self-confidence, bravity and hard work for a long life with physical disability. Children aged 17 years and adults who have lived with physical disabilities since age 17 years and below were considered in the research. 17 years was chosen because it is a transition period to adulthood as anybody who became disabled before the age of 17 has childhood experiences with parents on what they imparted in him or her.

### **Objectives of the Study**

The objectives of the study were to:

1. Find out the experiences and challenges of children living with physical disabilities.
2. Find out the parents' impact in their children living with disabilities in development of positivity, self-confidence, bravity and hardwork for a long life with physical disability.

### **Methodology**

Cross-Sectional Survey design was used to collect data at one point in time from a sample selected to represent a larger population. This study was conducted in Makueni and Kitui Counties in Kenya, targeting children with physical disabilities aged 17 years and physically disabled adults who became disabled at the age of 17years or earlier.

### **Findings**

- The study revealed that many of the persons living with physical disabilities have a lot of challenges, experiences and untold stories behind their disabilities, which they would wish to share.
- The study found that for children with physical disabilities, Parents play a key role in their physical, mental and emotional development.

- The family unit is supposed to be an avenue of love, respect, understanding, affection, sacrifice and childcare.
- There are virtues that children with disabilities learnt from their parents, while others are imparted in them through persuasion, dialogue and intimidation.

### **Recommendations**

- All the stakeholders dealing with persons with disabilities to organize regular forums for them to share their experiences, challenges and vent out their frustrations.
- Encourage parents to play their role in mentoring their children with physical disabilities.
- Encourage the PWDs to attend conferences organized by KISE and other institutions.

### **Plenary Session**

#### **Inclusion and Special Schools**

Inclusion has not been fully understood not only in Kenya but the world at large. There is no defined mode on how to go about it.

#### **Highlights**

- Deaf people are said to have a hidden disability. When all others are being considered disabled, they tend to be forgotten because nobody can tell that a person is deaf unless they interact with them.
- There is a gap in our education system in terms of transition. The government has done a good job in special schools not only for the deaf. In primary school's teachers can sign, unlike in many tertiary institutions.
- Students with special needs and disabilities have not been catered for appropriately in tertiary education.
- There is need to provide sign language interpreters at all levels of education for inclusion.
- Infrastructure in many universities is not friendly to people with disabilities.

#### **The Role of World Bank in the Lives of Children with Disabilities**

The World Bank categorizes its services in relation to children with disabilities into three; creating an enabling environment for inclusion and equity, operationalizing inclusive and Trust Funds to support governments towards Inclusion.

#### **Highlights**

- Aspiration to have all World Bank investments be disability inclusive by 2025.
- World Bank provides low interest loans to governments to promote inclusive education.

- The Bank provides specific activities and components to help task teams working with governments.
- The inclusive education resource guide provides different stages of the project. It focuses on preparing the project and consultations therein and to create components within the project.
- The main criteria that has been proposed within this resource style, is to support Disability Inclusion in Education including stakeholder engagement.
- There is also analysis which involves understanding the challenges these children face in accessing education. Inclusive project design ensures there is monitoring and assessment.
- There are two programs that offer financial aid and these are: Disability Inclusive Education in Africa Programme and Inclusive Education Initiative.
- Success of learning in schools depends on parental involvement, community perceptions and attitude, provision of assistive devices, learning materials and accommodations, additional out-of-pocket expenses, community infrastructure and transportation.
- In a study of 815 families across the country on parental attitudes, the most significant findings were that parents had a very strong belief in their child's education and aspired for their child's education. They only wanted their children to attain the highest level of education.
- Parents and caregivers of children with sensory and physical disabilities feel more confident to advocate for their child's needs at school. They said it was easier for them to advocate for their child's needs as opposed to parents of children with cognitive and psychosocial disabilities.
- Model of inclusive education is not a wrong approach only that resources are going to special schools and trained teachers are going to special schools.
- Another study had the same findings that special schools were more likely to access information and communication technology and better staffed with teachers who could help these children use the technologies better. This is one thing we need to look at in terms of resource allocation moving forward.
- From the landscape review of ICT for Disability Inclusive Education in Kenya, one of the key lessons is that for technology to work, we have to invest in the human aspect. Teachers and parents need more expertise on ICT and access to successfully support children with disabilities to access and take advantage of EdTech. For example, there is one organization called Lughu-Ishara a video-based sign language that had to provide sign language classes to the whole family to enable effective communication during the covid-19 pandemic.
- There are additional out-of-pocket costs that families of children with disability incur in supporting their educational participation. Across the countries, areas that parents face additional expenses were identified and these include:
  - Assistive devices
  - Transportation costs for adapted or accessible vehicles
  - Adapted learning materials
  - Expenses for personal care assistants

## **Key Takeaways**

- The need to invest in developing assistive technology service delivery systems and rehabilitation services.
- Pave way for accessible public transportation and barrier-free environments in communities.
- Create holistic approach for continuity between support and learning materials at school and home.
- Advocate for government to set up social protection programs including cash transfers and stipend to help parents meet those costs.
- There is an upcoming work at the Bank on empowering families to leverage on community resources for inclusion in Education in partnership with Inclusion International.

## **Questions**

**Question:** There is a concern regarding adults who have lost their eyesight and access to resources especially assistive devices. Please advice.

**Answer:** When I mentioned the frame works by the World Bank in relation to issues Inclusivity in education, the frame works and assistive devices cover all levels of education. The bank is also looking on programmes that facilitate access to resources in supported countries so they can engage effectively and gain skills. We have programmes that look at access to health services, digital skills and so forth including transport to aid persons with disabilities.

**Question:** What mechanisms are in place for parents who have children with extreme disabilities and are fully dependent on them?

**Answer:** The World Bank provides loans and finances to governments to facilitate their programs. We may not know the programs that are provided for institutional care or for persons with severe disabilities as the Bank only supports governments and the rest is up to them.

## **Legal instruments**

- Create awareness on legal instruments to enable parents to understand policies that protect their children's rights.
- There is need to develop policies to guide comprehensive functional assessment of children with disabilities and create synergies between the Ministry of Health, Social Protection and other stakeholders involved in functional assessment.
- MoE to develop a structure for implementing home-based learning for children with severe disabilities.
- MoE to act on the 15 promises made to learners and trainees with disabilities in the sector 2018 policy to enhance inclusion.
- There is need to enforce policies on involvement of parents in their children's transition.
- The government to fast track implementation of policies on accessible public transport.
- Teachers trained in SNE to be deployed according to their areas of specialization to enhance support of children with special needs and disabilities.

- Empower parents to advocate for their children with special needs and disabilities through their associations.
- Stakeholders to work in collaboration to make the world more accommodative to children with disabilities.
- Support parents to carry out home-based therapy by training and providing them with handouts and illustrations to use as references.

### **Parental Empowerment**

- Sensitize parents on different types of disabilities and available support services through different forums.
- Encourage parents to avoid being overprotective.
- Encourage fathers of children with disabilities to participate more in their children's functional assessment and education.
- Establish psychosocial support system for parents of children with disabilities and also encourage parents to establish parental support and lobby groups.
- The government to provide parents with assistive devices to support their children at home so that learning continues without regression.
- The government to establish economic empowerment programs for parents of children with disabilities. Income-generating activities that should be tailored according to their needs because parents of children with severe disabilities may not get caregivers for their children.
- Involve parents in decision making at all levels.

### **KISE**

- The Government to consider making KISE autonomous so that it devolves its services to counties.
- Be a central production and procurement centre for specialized learning resources, assistive devices and latest technologies for schools.
- Establish a data centre on SNE and disabilities to improve service delivery.
- Establish a centre for nurturing skills of learners and trainees with disabilities.

### **Functional Assessment**

- Need for early identification and intervention.
- Need for multidisciplinary approach to functional assessment.
- Parents to be involved in planning for assessment and intervention for their learners.
- Psychosocial support for parents to be a core component of functional assessment.
- The government to ensure equitable services for children with special needs and disabilities countrywide, both in urban and rural areas.
- MoE to establish modalities of continuous assessment of children with disabilities so that progress can be tracked.
- Review structures for functional assessment from the National to county level.
- MoE to equip EARC centres appropriately and ensure adequate manpower.

- Develop standardized functional assessment tools for all areas of special needs and disabilities.

### **Technical and vocational training**

- Adapt the curriculum for Technical and Vocational Training to suit learners with various special needs.
- Revive sheltered workshops in schools for children with intellectual disabilities and create awareness on their significance.

### **Accessible Learning**

- Institutions should make their environments accessible to all to enhance inclusion.
- Provide learners with disabilities with specialized learning resources, assistive devices and technologies.
- All teachers should be trained on special needs and disabilities to enable them identify and screen children with disabilities in their classes for intervention.

### **Learner Support Assistants**

- The government to invest in training and employment of learner support assistants in order to enhance support for children with disabilities in school.

### **Inclusive Education**

- This should be defined in a broader perspective rather than disability focused.
- Special schools should not be abolished. The sector policy acknowledges that children could be placed in inclusive settings while those with severe and multiple disabilities can be served in special schools.

### **Pre-Primary Education**

- The County governments in collaboration with the MoE should establish Special Pre-Primary schools to serve children with severe and multiple disabilities.
- Train pre-primary teachers on inclusive education.

### **Media**

- Mainstream media to continue sensitizing the society on issues of disabilities.
- The media to air more programmes where parents share their stories on raising their children with special needs and disabilities to motivate others.

### **Insurance**

- It is important to engage insurance companies in future in such forums to explore possibilities of developing medical insurance covers for children with disabilities.

### **Comments**

There is need of syncing the NHIF and the disability card. Working with MoH will enable parent's access these facilities for their children.



Parents need to be empowered so that they can engage with their children. There is a communication gap, especially on activities given by teachers (CBC) for learners with hearing impairment. Sometimes you give a task to the learner the parents may not be able to guide them because of communication barrier. The government should support these parents through programmes where they can be trained in basic sign language.

Organizers of conferences should be giving policies related to disabilities in booklets in summarized form. Some parents might not be able to download these policies.

An appeal to the government that caregivers/parents of children with disabilities be exempted from paying taxes.

## **CLOSING REMARKS**

### **Chairman KISE Council**

He noted that special needs education is part and parcel of the education system in Kenya. In the past ten or fifteen years, the government of Kenya has done very well to ensure that children with special needs and disabilities are given good attention and the necessary support they require. It is all about accessibility, inclusion and it entails infrastructure. Infrastructure in special schools is adapted and modified to suit the needs of learners, but after leaving special schools they face challenges. Inclusion will be possible if we have the right attitude from the family setting.

### **Highlights**

- There is need to create awareness and sensitization in the community to promote inclusion.
- Presence of trained teachers: the ratio of teachers to students also matters and that is all about resources.
- An appeal to the government to increase funding to schools that offer special needs care to children.
- It is important to note that inclusion does not replace special schools. They complement one another.
- Implementation of inclusion should be our main agenda.
- Not everyone is born with special needs but one can acquire it at any time in life. Therefore, this area of special needs is an area that should be given extra attention that it deserves.

### **Teacher Service Commission and KISE Council member**

- The presenter confirmed that the TSC has posted trained teachers to all schools and there are systems in place.
- The minimum qualification for teachers in a special school is a diploma in SNE from KISE.
- Teachers with special needs are also employed.

- The presenter implored parents to take their children with special needs to school.
- The presenter urged all to support teachers in their work.

### **KICD and Member KISE Council**

The presenter noted that parents who are empowered tend to provide better services to children with disabilities. Research world over has communicated very clearly that a child whose parent is empowered and learning institutions engage them, these children are better placed and have better opportunities in the world of work. In this respect, KICD has Parental Empowerment and Engagement Guidelines as one of the initiatives in the curriculum reform process.

The presenter pointed out that, we cannot be focusing on the intellectual development of the child at the expense of other dimensions, parental empowerment and engagement is very crucial. Parents are going to be our primary subject matter in education. In addition, she emphasized on empowering parents by coming up with engagement programs. It is only after the parents are empowered then they can be engaged meaningfully and it cannot be the other way round.

### **Director, KISE**

The director appreciated all participants for their attendance and active participation in the conference. The presenter thanked the key note speakers, presenters, invited guests, members of the KISE council and parent leadership. The presenter also appreciated the entertainment group.

### **Highlights**

- The conference presented space and platform for parents of children with disabilities to express their feelings and emotions. “You have written history in what you have discussed in this forum”, he commented.
- The conference was the first one of its kind and nature to be held in the country. This is the first step towards the right direction.
- Parents’ organizations and health providers will be included in planning the next conference of the same nature.
- He encouraged parents to campaign and help others bring their children for functional assessment and early intervention.
- There is a Disability Entrepreneurship programme in the Institute which was stated in the year 2022 meant to help those willing to undertake government offers since 30% of all tenders in the government are supposed to go to the youth, women and PWD.