

Early childhood intervention: the Gauteng experience

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ECI is defined as the experiences, opportunities, support and resources provided to children with developmental delays, disability, and those who may develop delays due to biological or environmental factors.

In 2010, the Rehabilitation Sub-Directorate of the Gauteng Department of Health started a consultative process on early childhood intervention (ECI) to address the challenges experienced by children and their families in accessing services in the province. As a result of the expressed need for improved coordination and leadership of ECI, a provincial multidisciplinary workgroup was formed that included a variety of healthcare professionals as well as representatives with expertise and interest from other government departments and universities. The workgroup prioritised a few key areas. These included providing ECI training for professionals, improving inter-sectoral collaboration, and at a higher level, motivating for the inclusion of ECI in provincial policy directives to include adequate budgeting, human resource allocation, and the development of tools for monitoring and evaluation. Various

stakeholder engagements were held with other government departments, universities, advocacy groups and non-profit organisations. Capacity building for practitioners was set at two training workshops per year and a biennial ECI conference.

The ECI workgroup also aimed to improve access to resources for the provision of ECI services in the province. This has been facilitated by the development of brochures on child development for caregivers of young children, a biannual newsletter, as well as updates on local and global initiatives and practice for healthcare professionals.

The chapter outlines the challenges experienced in the implementation of ECI in Gauteng, and recommendations are made for a way forward.

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Introduction

Childhood is a critical period in the development of human and social capital.¹ International governments as well as human rights and development organisations have led a global call for all young children to have access to quality services that improve their health, nutrition, learning and emotional well-being. The environment and experiences provided for young children and their families affect not just the developing brain but also many other physiological systems.² Early childhood intervention (ECI) is defined as the experiences, opportunities, support and resources provided to children with developmental delays, disability, and those who may develop delays due to biological or environmental factors.²⁻⁵ ECI also focuses on providing informal and formal social networks that support family patterns of interaction, promote child development outcomes, and facilitate family functioning and well-being.^{3,4}

South Africa has demonstrated its commitment to realising children's rights at the highest political level by ratifying the United Nations (UN) Convention on the Rights of the Child,⁵ the African Charter on the Rights and Welfare of the Child,⁶ and the UN Convention on the Rights of Persons with Disabilities,⁷ as well as the Sustainable Development Goals.⁸ Section 28 of the South African Constitution provides children with an unqualified right to basic shelter, health services, nutrition and social services.⁹

The following policies support the focus on children in South Africa:

- The National Health Act (No. 61 of 2003) makes provision for free healthcare and assistive devices to children under the age of six years.¹⁰
- The Children's Amendment Act (No. 17 of 2016) takes into consideration a number of aspects that relate to child health, development and disability.¹¹
- The first 1 000 days of life is increasingly recognised as a period of opportunity for the foundation of optimal health and development across the lifespan.¹² In addition to the re-launch of the Road-to-Health Booklet (RTHB) in 2018, the national under-5 Side-by-Side campaign has strengthened the National Department of Health's (NDoH) focus on child development.¹³
- The planned National Health Insurance (NHI) looks at improving access to health care for children and their families.¹⁴
- The 2015 White Paper on the Rights of People with Disabilities, specifically Strategic Pillar 4, emphasises the empowerment of children, women, youth and persons with disabilities.¹⁵
- The NDoH Framework and Strategy for Disability and Rehabilitation 2015-2020 (FSDR) aims to provide accessible, affordable, appropriate and quality rehabilitation services throughout the life course.¹⁶
- The National Development Plan 2030 identifies the importance of ECI.¹⁷

- The 2015 National Integrated Early Childhood Development Policy recognises ECI as one of the priority areas for young children.¹⁸

The commitment to ECI is also echoed at provincial level. Sub-programme 4.2.5 of the Gauteng Health Department's (GHD) Annual Performance Plan 2018/19-2020/21 commits to reducing perinatal and neonatal morbidity and mortality.¹⁹ A situational analysis of disability in South Africa done in 2011²⁰ found that there were approximately 243 000 children with disabilities between the ages of 0 and 4 years.

Gauteng is the fastest-growing province in South Africa, with a population of 14 million people, of whom approximately four million are children. It accounts for the largest share of the South African population.²¹ Forty-nine per cent of children live with both parents, and at least 21% live in overcrowded homes.²² In 2018, 2.1 million South African children lived in homes that reported child hunger, with one-fifth of this number living in Gauteng.²³ By the end of March 2019, there were more than 630 000 child beneficiaries of the child support grant in Gauteng.²⁴

Young children with disabilities often miss out on intervention services and family support in the first few critical years of life.²⁵ This can lead to their difficulties becoming more severe, often leading to lifetime consequences, increased poverty and profound exclusion.^{26,27} Early identification and initiation of treatment have been shown to improve child outcomes; however, the under-identification of children with disabilities in South Africa is of concern.²⁷⁻²⁹ The earlier a child is identified as having a developmental delay or disability the greater the likelihood that the child will benefit from intervention.²⁸ The only developmental surveillance or screening tool implemented nationally in South Africa is the RTHB,²⁹ which was revised in 2018.³⁰ However, optimal use of the RTHB, especially for developmental monitoring, is dependent on knowledge and co-operation among mothers, caregivers and healthcare workers implementing the tool.³⁰⁻³²

Establishing the work group

In 2010, the ECI workgroup was established under the leadership of the Rehabilitation Sub-Directorate of the GDH. The workgroup members include representatives from the Rehabilitation Sub-Directorate, therapists working in the public health sector (Audiology, Speech Therapy, Physiotherapy, Occupational Therapy, Dietetics, Podiatry, and Social work), and representatives from some academic institutions. Initially, workgroup membership was voluntary, but today interested parties must submit their curriculum vitae and a letter of motivation for review and acceptance.

The workgroup has approximately four to six meetings and a strategic planning session annually. The latter includes a

SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis, a review of the year's activities, and planning for the following year. In 2018, as part of the strategic planning process, a terms-of-reference document was developed to improve commitment and accountability. Appointment letters clarifying the responsibilities of each member are accepted by the Deputy Director for Rehabilitation. The terms-of-reference document has had a positive effect, with improved attendance at meetings and increased accountability in planning and implementing workgroup activities.

The workgroup held a consultative planning workshop in 2011 and identified the following key concerns in the province:

- Lack of governance and leadership
- Late identification and referrals
- Intersectoral collaboration
- Capacity building.

Lack of governance and leadership

According to the World Health Organization's health systems strengthening framework, leadership and governance form the first building block in ECI.³³ Leadership needs to: ensure that a policy framework is available, facilitate collaboration across sectors, provide an overall vision for an ECI service model, and ensure effective leveraging of resources across sectors.³³⁻³⁵ Those leading and managing health systems are often not adequately prepared, and leadership efforts often do not produce the desired outcomes.³⁶

The consultative process of the workgroup revealed lack of clarity regarding custodianship of ECI in the province. There was also no guidance on ECI implementation. The workgroup therefore identified the need for an ECI policy and a strategy to facilitate integration of ECI principles into daily practice in the public sector. Over the past 10 years, the ECI workgroup has frequently discussed the development of a provincial ECI policy. The policy was first drafted in 2010 and underwent a number of revisions before submission to the Head of the GHD in 2018. The workgroup is still awaiting approval and finalisation.

The urgent need expressed by therapists for assistance in implementing ECI led to the development of an intervention framework. A "Guide to getting started" document was developed in 2012. It focused on enabling ECI services to empower parents and caregivers to be the primary facilitators in their child's development. The document also provides key principles and recommendations on how to establish and sustain ECI programmes within the public health service.

Late identification and referrals

A global strategy is needed to narrow the gap between early identification and the increasing population of children with delays and disabilities.³⁷ It has been indicated that the best time to prevent conditions that could cause developmental difficulties and impact brain development is during infancy and early childhood.³⁸⁻⁴⁰ Early identification and referral

should therefore be an integral part of all clinical contact and planning and should be included routinely in the training of all healthcare workers.³⁷ Therapists within the province have repeatedly expressed their concern about children being referred too late for effective intervention. ECI services for young children in Gauteng remain fragmented and, where present, are often of variable quality. The guide-to-getting-started document recommended strategies to improve early identification and establish effective referral pathways.

Intersectoral collaboration

Intersectoral collaboration enhances interventions that aim to improve child well-being and address the social determinants of health.^{40,41} Historically, services in early childhood have been fragmented between health and education systems.^{28,42} Collaboration between different government departments requires political direction, initiation and coordination. The workgroup therefore recommended that the Office of the Premier be the custodian of ECI services in the province. This recommendation has however not been actioned by the Office of the Premier. Intersectoral collaboration creates a framework to promote ECI.^{33,42} The ECI workgroup held various stakeholder engagements with other government departments and ECI partners, namely the Department of Social Development, oral health practitioners, district clinic specialists, obstetricians, paediatricians, nurses, universities, advocacy groups and non-profit organisations. These engagements have mainly aimed to improve understanding of the role of various stakeholders in strengthening referrals and increasing utilisation of community-based resources.

Capacity building

Healthcare workers are primarily trained in the treatment of acute childhood illness, often with limited sensitisation or training in holistic child development or recognition of neurodevelopmental delays.³⁷ This sentiment has been expressed by participants at workshops and conferences in the province. The field of ECI has long been recognised for its interdisciplinary service delivery to infants, young children and their families. However, there are no consistent standards or competencies to guide the different disciplines to jointly implement common areas of ECI practice.⁴³ The workgroup conducted an email survey to determine the services available at all levels of care, as well as the training needs of therapists in the public health sector. The lower-than-desired response rate (57%) could be attributed to lack of internet access and poor communication structures within facilities. Telephonic interviews were conducted with therapists at sites that did not respond initially, which allowed information to be obtained from 96% of the institutions. The results showed that services were fragmented, facility-based, and entrenched within a medical model of service delivery.

Specific problems reported included families attending multiple appointments (e.g. up to five appointments with different professionals within a short period of time), poor coordination of care, conflicting information provided to

families, and significant cost implications that resulted in poor attendance. It was also reported that healthcare centres were developing profession-specific resources in isolation, and that there was limited networking between departments and with community organisations.

Collaborative and coordinated teamwork has been identified as best practice in ECI as it facilitates pooling and exchange of information, knowledge and skills, and working together cooperatively.^{44,45} Collaboration and teamwork are critical to ECI, especially when addressing the diverse needs of children with disabilities or those at risk for developmental delays.⁴⁶ An integrated team approach is recommended to improve the efficiency and effectiveness of ECI services.²⁸

The following areas were identified as training needs at all levels of service delivery: how to implement and improve

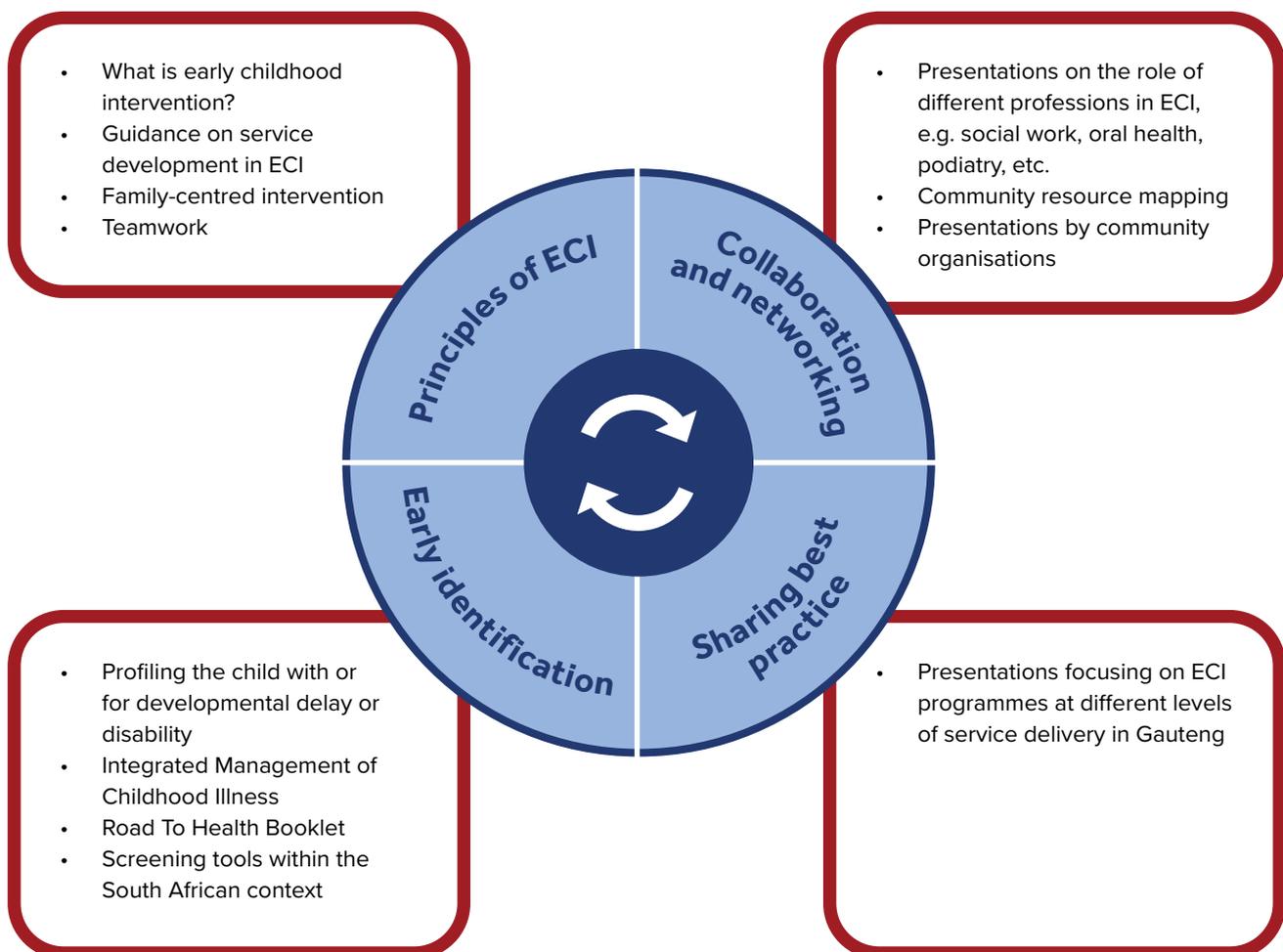
ECI services, developing and working in ECI teams, sharing best practice models of ECI, setting up developmental screening services, sharing of resources, networking and collaborating with other stakeholders, understanding policy, and referral pathways. These identified needs may also inform improvements that need to be addressed at a pre-service curriculum level.

Capacity-building activities facilitated by the ECI workgroup include hosting workshops and conferences and developing and sharing resources.

Workshops

The content of the workshops was planned in alignment with the identified training needs and developments in the province. Figure 1 indicates the topics covered at the workshops.

Figure 1: Topics covered in the ECI workshops, Gauteng 2010-2020



The workgroup has developed task sheets that clearly define the roles of members in implementing the workshop. The number of attendees at each workshop is restricted by the size of the venue available and the number of staff who can be released for the day. The workgroup has facilitated 13 workshops from 2011 to 2020, with an average of 105 attendees at each workshop. The format has evolved into a more participatory approach since its inception. The design includes a welcome address, an introduction to the theme, and multiple presentations related to the theme. The participants are divided into smaller groups for interdisciplinary team discussions, facilitated by members of the workgroup. The discussions have focused on case studies, which integrate the theory covered and tools shared. Over the past three years, the workshops have included a presentation by a parent or recipient of ECI services, with the aim of sensitising healthcare workers to family-centred intervention. Participants have reported this to be a valuable contribution in helping to change their attitudes towards working with families.

Evaluation and conclusion of the workshop includes verbal feedback on how participants would apply the information gained to their work context. Evaluation forms are completed at the end of each workshop to improve the content and processes of future workshops. Themes that have emerged from participants regarding implementation have included improved teamwork at facility level, better understanding of the role of other professionals, increased understanding of family-centred intervention, and increased use of the RTHB Integrated Management of Childhood Illness and A Guide for Monitoring Child Development.^{13,47,48}

The workgroup had a workshop planned for September 2020. Due to COVID-19, this workshop was hosted on an online platform and explored the continuation of ECI services during the pandemic at different levels of service delivery. The presentations focused on strategies employed by therapists, including, among others, telehealth.

Conferences

The task team has hosted three ECI conferences in Gauteng. The conferences have provided a platform for therapists, other health workers, academics and researchers to showcase their work in ECI. The first conference, in 2015, themed 'Early Childhood Intervention – The South African experience', included presentations on ECI practices in Gauteng, the Western Cape, the Northern Cape and Kwazulu-Natal. The feedback from 100% of attendees indicated a positive learning experience. They specifically highlighted the variety of presentations and the combination of research and practice. Most (90%) of the attendees agreed that they would be able to apply the new skills that they had learnt. The second conference in 2017, focused on 'Strengthening Early Childhood Intervention', and presentations covered intervention in the neonatal population, strengthening ECI services through stakeholder engagement, partnering with parents, patient-centred care, and ensuring the well-being of therapists. Attendees highlighted the value of multiple

perspectives, and reported an improved morale and motivation to understand and implement the link between research and practice in ECI. The last conference, held in 2019, highlighted 'Research to practice in ECI: A South African perspective'. The presenters shared screening tools validated in the South African context, discussed the traumatic realities of children described as intersex, contextualised ECI in South Africa, and highlighted a number of clinical research initiatives undertaken at different institutions. At all three conferences, presenters and attendees included varied professional groups, parents, non-profit organisations and academics.

Child development brochures

The ECI workgroup has developed a series of pamphlets focusing on children from birth to six years of age. The pamphlets cover developmental milestones, ideas on play and stimulation activities for families, and developmental warning signs. The pamphlets were piloted at two clinics in Gauteng where therapists and patients provided feedback on the content and graphics. The main changes after piloting related to the content, which was changed to more patient-friendly language. The graphics were deemed appropriate for the context. The pamphlets are currently only available in English and will be translated when funding becomes available. They have been shared electronically with all service sites in Gauteng and are available on request from the Gauteng Rehabilitation Sub-Directorate. The pamphlets are being used in conjunction with the RTHB at well-baby clinics, neonatal follow-up clinics, and developmental care talks to parents.

Biannual newsletter

The newsletter was started in 2014 and includes educational information, patient journeys, advertisements on upcoming courses, and motivational pieces. The newsletter is shared electronically with healthcare professionals working in the field.

Additional workgroup activity

The workgroup has been involved in advocating for the implementation and sustainability of effective ECI services. Various members of the group have presented papers on the Gauteng ECI experience in Sweden, Turkey and Kenya. A chapter on child disability and the family in the book *Children in South African Families: Lives and times*⁴⁹ was also published by team members in 2016. Workgroup members have been invited to present to the ECI sector, profession-specific forums, and other organisations, e.g. UNICEF, the Child Health Priorities Conference, and the National Rehabilitation Forum. These invitations to share the experience of the workgroup indicate the value of the work being done.

During the COVID-19 pandemic, workgroup members have been sharing information on webinars in the field of ECI as well as resources for children and their families. A questionnaire has been distributed to institutions about the type of services being offered to children and their families, as most institutions have limited outpatient services.

Outcomes

The workgroup's activities have resulted in an increased awareness of ECI at all levels of care; however, this has not been measured systematically. Most districts in Gauteng have implemented targeted ECI programmes, including developmental and hearing screening for high-risk infants, and support groups and workshops aimed at caregivers of children with or at risk for disabilities and developmental delay. The workgroup has also encouraged healthcare professionals from other provinces to coordinate initiatives in their provinces. The main impact of the workgroup activities has been gathered from feedback received at workshops and conferences.

Challenges

The workgroup has recognised a number of challenges in the implementation of ECI in Gauteng. There is an absence of visible and coordinated leadership of ECI in the province. The major role player remains the provincial Department of Health, which does not have a mandate to influence other provincial departments such as the Gauteng Department of Education. The workgroup members volunteer their time and expertise, which restricts the number of activities planned each year. The absence of a provincial ECI policy has resulted in fragmented services within a medical model of intervention. As a result, institutions cannot be held accountable for implementation, and the impact of services cannot be measured. Unfortunately, the statistics currently collected only focus on the number of children screened and the assistive devices issued. The lack of a dedicated budget for ECI has implications for human resources as well as planned activities and resource development.

Way forward

The critical challenge facing ECI is how to capitalise on current evidence-based knowledge and context-specific experiences, mobilise collective resources, and improve the quality of services through authentic family engagement to ensure better health and development outcomes for children and their families.⁵⁰⁻⁵²

The workgroup will continue to pursue the adoption and implementation of an ECI policy within Gauteng. ECI needs to become a national priority at policy level, with appropriate indicators to hold all stakeholders accountable. The workgroup will pursue its capacity-building activities in the province through workshops and through hosting its biennial conference. Stakeholder engagements will be sustained and developed further to facilitate and strengthen intersectoral engagement. The workgroup remains committed to ensuring that the best interests of children and their families are upheld through the services offered by therapists in the province.

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