

The intersection between Health and Education: meeting the intervention needs of children and youth with disabilities

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Intersectoral collaboration between the health and education sectors can strengthen intervention services for CYWD and facilitate improvement of their health and developmental outcomes.

Improving developmental outcomes for children and youth with disabilities (CYWD) in low- and middle-income countries requires the removal of access barriers perpetuating the patterns of exclusion of persons with disabilities in general. In South Africa, an upper middle-income country with stark characteristics of inequality, intervention and support are hampered by inadequate coordination, and confusion regarding roles and responsibilities between key stakeholders in the health and education sectors. The World Disability Report highlights poor coordination of services, inadequate staffing, and poor staff competencies as critical in determining the quality, accessibility, and adequacy of services for persons with disabilities. The South African National Departments of Health and Basic Education both have individual as well as coordinated policies that should facilitate the participation of CYWD in environments important to their health, development and academic abilities. However, there

is a disjuncture in how these policies are implemented at provincial, district, hospital, and school level when children transition between these sectors.

Drawing on bioecological systems theory, the chapter explores how intersectoral collaboration in the health and education sectors is affected by poor coordination and integration at various levels of the system for CYWD. The chapter further proposes how rehabilitation professionals working in these two sectors and delivering intervention services at grassroots level, can start to use a biopsychosocial approach, such as the International Classification for Functioning, Disability and Health, to transform their practices and improve coordination of roles and responsibilities. This would allow CYWD to transition more seamlessly between these sectors, mitigating the systemic barriers that lead to inadequate health, development and academic outcomes for disabled children.

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Introduction

The Alma-Ata declaration¹ defines health as a “state of complete physical, social and mental wellbeing and not only the absence of disease or infirmity”. This definition supports a shift from a curative to a comprehensive model, inclusive of the psychosocial aspects of care within a primary health care (PHC) approach. More recently, the Global Conference on Primary Health Care in Astana,² developed a new declaration that refocuses the Alma-Ata commitment to PHC, with additional emphasis on Universal Health Coverage (UHC) and the health-related Sustainable Development Goals (SDGs). For South Africa, this renewed commitment has particular relevance for children and youth with disability (CYWD) since international³ as well as local reports^{4,5} have indicated that they still have many unmet health and rehabilitation needs and consequently poor health and development outcomes.

The health and development of CYWD cannot be achieved in isolation. This links and depends on core principles outlined in the United Nations Convention of the Rights of People with Disabilities (UN CRPD), such as non-discrimination, autonomy, participation and social inclusion, respect for difference, accessibility, equality of opportunity, and respect for the evolving capacities of children.⁶

Childhood disability in South Africa

Disabled persons, including children and youth, make up a significant section of society. Although there are no recent or reliable disability statistics available for CYWD in South Africa, some reports suggest the prevalence rate to be in the region of 11%.⁷ The poor availability of data may be due to discrepancies in results obtained from different questions and methods used in various population-based surveys.⁸

Children in South Africa are affected by a triple burden of disease that includes maternal and neonatal healthcare challenges, high prevalence of HIV and TB, and high levels of community violence and trauma.⁹ In addition, the majority of children in South Africa (63%) grow up in poor households.¹⁰ Together, these factors increase their risk of acquiring a disability.¹¹

Meaningful participation: the long-term goal for CYWD

An important component in the right to health is access to interventions that are promotive, preventive, and rehabilitative. The goals of these interventions for CYWD

should be those we hold for all children, namely that they have the functional capabilities to participate meaningfully in all aspects of their lives and in all aspects of society.¹² The goal of meaningful participation for CYWD is encapsulated in the World Health Organisation’s (WHO) International Classification of Functioning, Disability and Health (ICF).¹³ The literature to date is consistent in showing that CYWD participate less frequently in home, social, and educational activities than their peers without disabilities.¹⁴

The ICF defines health not as an absence of disease, but as “the complete physical, mental, and social functioning of a person”.¹³ Within this biopsychosocial framework, disability is seen as a function of the interaction between a person’s health condition (i.e. biomedical condition or impairment) in terms of body functions and structures, together with contextual factors in the environment and in the person, all of which can either hinder or facilitate development.¹⁵ By taking into account contextual factors that can affect health, the ICF acknowledges the social determinants of health.¹⁶ This is particularly relevant in a country like South Africa, an upper middle-income country with stark characteristics of inequality (Gini coefficient 0.67), which contribute to the country’s high burden of disease.¹⁶ Participation for CYWD can be limited, especially in resource-constrained environments and where impairment limitations are exacerbated rather than ameliorated by environments that are unsupportive and inaccessible.¹³

Participation challenges for CYWD

While ratifying many of the social-model approaches, such as the UN CRPD, South Africa still largely follows an impairment or medical model in many of its planning and intervention services for CYWD.^{17,18} There is often overt reliance on a diagnosis, resulting in restrictive eligibility criteria for accessing services and support, which is not always consistent with the ethos of policies based on a social model. South Africa’s White Paper 6,¹⁹ an education policy that promotes an inclusive approach for children with disabilities, is one such example that has not resulted in significant gains for CYWD participation in an inclusive education system.²⁰ Many CYWD are still not attending an educational facility, and when they are, the education system reflects a segregated, parallel approach where CYWD are placed mainly in special schools for specific types of disabilities.²⁰ This is a major obstacle to their inclusion in mainstream education. There is also a growing concern about the increasing calls to and plans from Government to expand such schools,²¹ despite this being against stated policy.

Intersections between Health and Education

Intersectoral collaboration between the health and education sectors can strengthen intervention services for CYWD and facilitate improvement of their health and developmental outcomes. Intersectoral collaboration

refers to the promotion and coordination of the activities of different sectors.²² Health planners have often identified education, agriculture, water and sanitation as sectors that can, and should, collaborate in helping to reduce inequities in health.²² Since the major determinants of health (i.e. the socioeconomic environment, the physical environment, and individual characteristics and behaviours) lie outside the healthcare system,¹⁶ it stands to reason that efforts to address inequities in health must incorporate sectors whose activities have a bearing (both directly or indirectly) on the health and well-being of CYWD. One of the most important sectors is education. The reported fragmentation and lack of collaboration between health and education can represent a failure to recognise the intersection of probably the two most important sustainable development goals (SDGs) for children and youth, namely SDG 3 (Good Health and Well Being) and SDG 4 (Quality Education).²³

There is a well-established body of evidence to show that educational attainment is one of the most important social determinants of health, with access to high-quality educational programmes having a significant influence on health and developmental outcomes for vulnerable children,²⁴ especially those with disabilities in low- and middle-income countries.²⁵ The research is clear that education outcomes achieved from early childhood education, through to primary school, high school and higher education are essential to good health outcomes.

This relationship between health and education has been further explained by Hahn and Truman.²⁴ Firstly, health is seen as a prerequisite for education. Children who do not have adequate nutrition, for example, face significant obstacles to their learning. In South Africa, malnutrition is one of the leading health issues facing children and youth.²⁶ For this reason, South Africa's National School Nutrition Programme (NSNP) provides one daily meal to over nine million learners.²⁶ When children are not able to access school it has a significant and debilitating impact on their health status. CYWD in LMICs are particularly vulnerable to food insecurity as they tend to come from some of the poorest households²⁷ and often have difficulty feeding themselves due to an impairment. A second principle connecting health and education is that education on health and the provision of health services in schools is seen as an important public health intervention.²⁴

Children with disability: traversing multiple systems

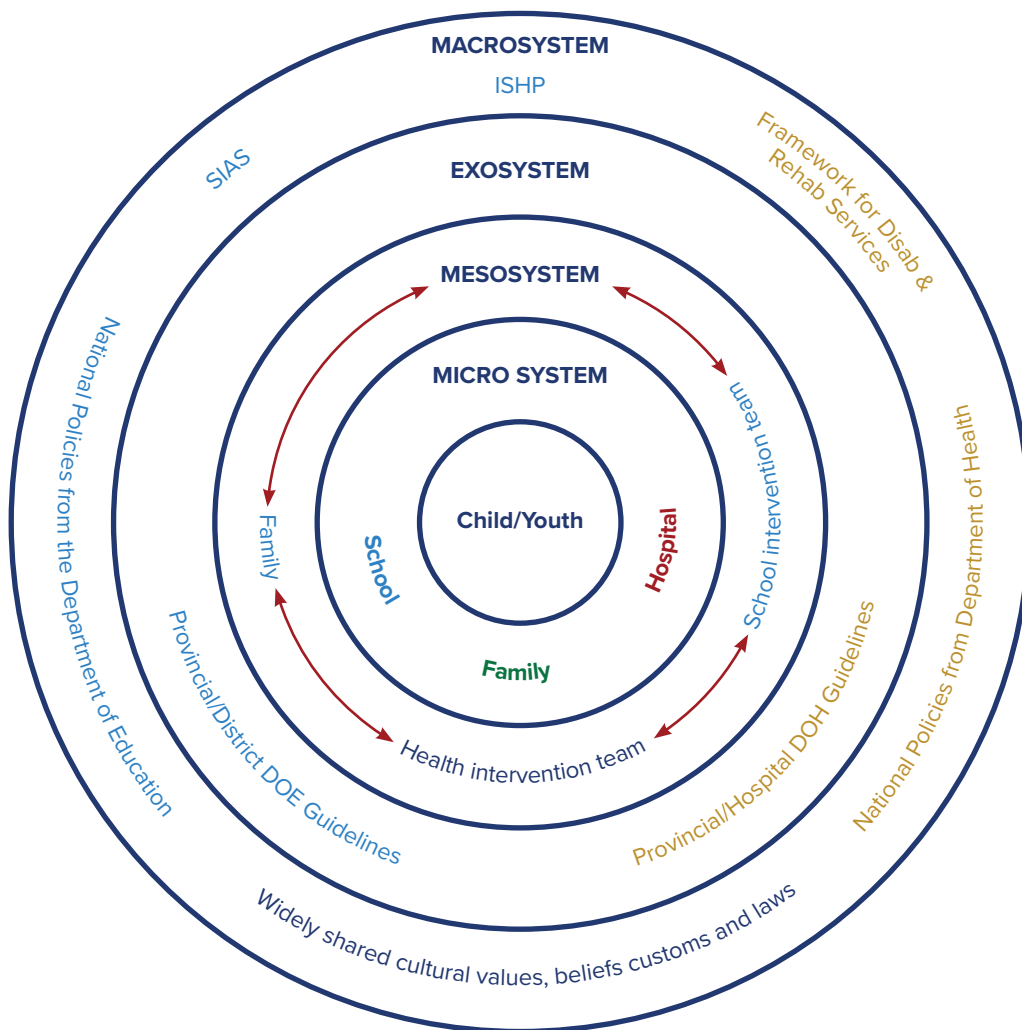
Over the course of the first two decades of their lives, CYWD are required to access interventions to accomplish promotive, preventive and rehabilitative goals. This requires traversing the healthcare and education sectors. Specifically, it requires CYWD to access services from a range of rehabilitation professionals (e.g. occupational therapists, speech therapists, physiotherapists) within the same sector and across sectors, including support such as assistive technology. Traditionally, intervention services for CYWD who move between the health and education sectors have been planned in isolation.¹⁸ This typically reflects a siloed approach, starting from the higher levels of isolated policy development for each of these sectors, down to sector-specific isolated interventions for children, with few links or collaborative practices between the two systems.¹⁸

Bioecological systems theory: understanding intersectoral linkages

Bioecological systems theory²⁸ (Figure 1) is used to explore the linkages between the education and health sectors at various levels of the system surrounding CYWD, and to understand the systemic challenges between the health and education sectors. For the purposes of this chapter, the focus is on CYWD of school-going age (between 6 and 18 years old) as they are more likely to come in contact with these sectors.

Systems theory seeks to explain the behaviour of complex, organised and interconnected systems and is a relevant method to understand the intersectoral operations of the health and education sectors.²⁸ In terms of the bioecological framework (Figure 1), policies that deal with CYWD fall at the macro level of the system. Macro policy inconsistencies may result in a lack of clarity in the exosystem, i.e. in terms of provincial departments that are required to effect these policies in guidelines and implementation strategies. This confusion is often reported anecdotally, as highlighted by an example reported in the less-resourced Eastern Cape province (Box 1). An example such as this is not new or unique to the Eastern Cape but is common in almost all provinces in South Africa.²⁹

Figure 1: Bioecological systems theory applied to intersectoral collaboration between the health and education sectors



Source: Adapted from Bronfenbrenner and Morris.²⁸

Box 1: Example of poor intersectoral collaboration

In many schools in the Eastern Cape, School-based Support Teams refer learners to the Department of Health (DoH) for intervention services and assistive devices. The Department of Basic Education (DBE) sees its role as supporting the educational needs of disabled learners by identifying them, placing them in suitable educational settings, and supporting their learning. When the learner reaches the DoH facility, he or she is often sent back to the DBE facility, as the DoH believes that the DBE has the available rehabilitation professionals to manage the intervention needs of children with disabilities rather than sending them to the

health institution. In this back-and-forth referral, with no services being provided to CYWD, their health conditions are further compromised and they end up suffering, with their rights being violated by these systems. There is thus poor intersectoral collaboration between the two micro-systems, with no strategic guidelines defining the roles of rehabilitation professionals in each of these departments. Each institution makes its own decisions on how to handle the CYWD referred to them, with 'gentlemen's agreements' and no written roles for who does what or who procures or is responsible for maintenance of assistive device equipment.

Recently, Van Niekerk and colleagues²⁹ undertook focus groups with rehabilitation professionals involved in assistive technology (AT) implementation for children with disabilities. Lack of prescriptive guidelines from the National and Provincial Departments of Health (DoH) and the Department of Basic Education (DBE), as well as fragmentation in AT procurement, were mentioned by professionals as being a challenge when children transition between hospital and school-based intervention services. Moreover, professionals reported that it was standard practice for children with disabilities to be discharged from hospital-based intervention services after they turned six years of age, on the assumption that services and AT supports would be provided by the DBE.

The study by Van Niekerk and colleagues highlights how the connections between the two important intervention microsystems within health and education for CYWD in South Africa, i.e. the mesosystem, can be weakened by policy and legislation barriers at higher levels of the system. A mesosystem is a functional component involving connections between two or more microsystems of a child (Figure 1).²⁸

Mesosystems that are weak or that have limited connections often result from a lack of coordination and collaboration at higher levels of the system, usually from isolated policy planning and development, or because the people who are tasked with effecting policy at lower levels do not have the capabilities to implement it.³⁰

Policies relevant to CYWD transitioning between Health and Education Departments

The vision of the DoH Framework for Disability and Rehabilitative Services 2015-2020,²² is to provide quality disability services across the life course. In its mission statement, the Framework acknowledges the importance of intersectoral collaboration with other government sectors, including education. However, it is largely silent on how this should take place in practice, and it hardly discusses the importance of children with disabilities moving between two sectors over the life course. It also does not specify how this policy framework links to relevant policies in the DBE, such as the policy on Screening Identification, Assessment and Support (SIAS).³¹ Nor does it discuss an important intersectoral policy between health and education, such as the Integrated School Health Policy (ISHP).³² The ISHP is one of the few coordinated policies developed between the DoH and DBE that recognises the intersectoral nature of health.³² It seeks to address the multiple health needs over the 12-year educational span for school-aged children and youth, and requires integrated collaboration across multiple sectors for it to be effective as

a public health intervention.³² For example, a lack of proper roads, transport, and staffing, means that healthcare teams would find it difficult to visit schools, especially in rural areas.³³ Pertinent to CYWD, identification and support of children with chronic health conditions is a required part of services in the IHSP.³² Of concern is that there are already indications that implementation of this policy is failing, due largely to poor communication, lack of collaboration, absence of consultation and involvement, inadequate resources, unrealistic workloads, and lack of training and development.³⁴ Lack of collaboration and coordination at an exosystem level between provincial Departments of Education and Health, infiltrate to levels lower down between school-based intervention and hospital-based intervention teams providing services and supports to CYWD.³⁵

The DBE's SIAS, governing the support to CYWD of compulsory school-going age, is more detailed in terms of its links with the health sector. For example, it specifies how rehabilitation professionals working in health can facilitate a seamless transition for children with disabilities entering the education system by formally documenting assessment and support information. It is also much more aware of its links to the ISHP in terms of promotion of health and development of CYWD.

It is clear that promotive laws and policies notwithstanding, ground-level implementation of macro policies at an exosystem level (i.e. provincial Department guidelines and strategies) and microsystem level (hospital and school intervention teams) continues to plague services and support for children with disabilities (Box 1). One way to address this would be to strengthen the links between the microsystems, i.e. the mesosystem (Figure 2) in terms of a bottom-up approach. One of the important drivers in strengthening mesosystems would be to support the people in these systems, specifically the rehabilitation professionals tasked with providing support and intervention to CYWD.

Training of rehabilitation professionals

Rehabilitation professionals in South Africa (speech therapists/audiologists, occupational therapists and physiotherapists) who are primarily tasked with providing intervention services to children with disabilities within the health and education sectors, still largely offer their services within a medical model with a focus on 'fixing' impairments.¹⁸ This occurs despite wide recognition that a biopsychosocial model is a more effective approach as it acknowledges that disability is largely an interaction between an impairment, and contextual and personal factors.¹³ Within the professions of speech therapy and audiology in South Africa,³⁵ as well as in occupational therapy,³⁶ there have been increasing calls for the rehabilitation professions to transform from

their colonial roots in which the medical model has been grounded. The medical model conflicts with the multi-sectoral and cross-disciplinary collaborative approach required when working with disabled populations.³⁷ Furthermore, the medical model perpetuates inequalities within service delivery in South Africa,³⁸ with the population most in need of services, namely poor, black, African-language speakers, unable to access or afford these services.³⁵

Professionals trained in the medical model often struggle to be responsive to the demands placed by the environment,³⁶ demands that either facilitate or hinder the ability of CYWD to participate meaningfully in important developing and enhancing contexts in the home, school and community. Medical-model training has thus resulted in rehabilitation professionals trained to fix developmental impairments, but not having sufficient knowledge and skills to support the inclusion and participation of CYWD in the South African education curriculum.³⁸ Currently, most public-service rehabilitation professionals in South Africa are employed at a tertiary level in the provincial DoH, while those in the DBE are based mainly at district level where they are required to support school clusters or certain special schools.³⁹

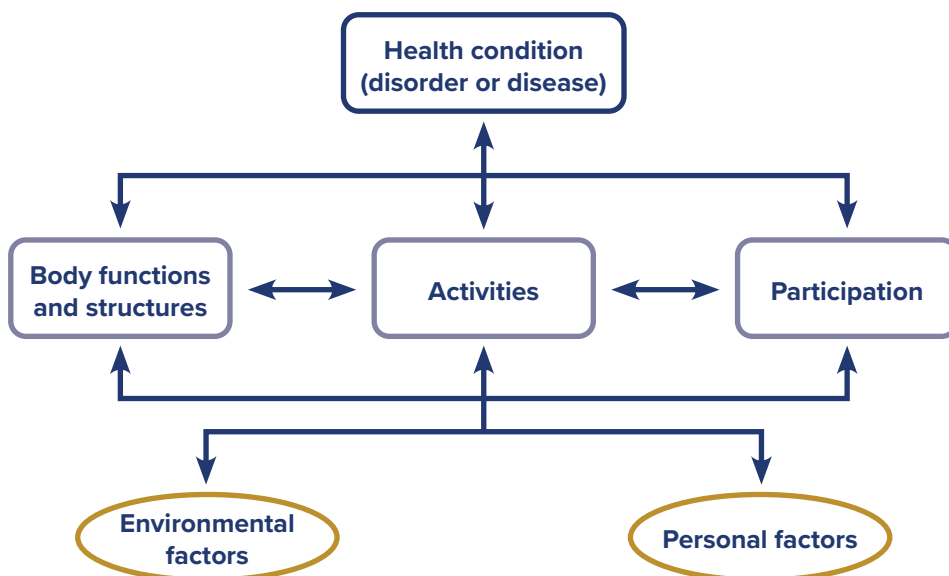
Training of rehabilitation professionals at pre-service level and within continuing education needs to transform radically if children with disabilities are to be supported seamlessly between their rehabilitative microsystems in health and education. A collaborative approach is needed

that works from the basis of common or shared goals and that acknowledges the role that the environment plays in facilitating or hindering development.

The ICF as a framework to assist collaboration within and across sectors

SDGs 3 and 4 mandate governments to promote the development of school-aged children and youth as healthy and educated citizens. While governments often develop separate departments to manage these services, CYWD frequently receive overlapping support from these sectors, making the separation of health and education a false dichotomy.⁴⁰ Publication of the WHO's ICF in 2001, reflected a paradigm shift from the medical model to a biopsychosocial model in terms of how disability is viewed. The ICF offers a common language for rehabilitation professionals in health and education to describe the functioning of CYWD across sectors, settings and individual disciplines.¹⁵ The ICF has traditionally been viewed in the context of the healthcare system. However, as a framework and a taxonomy it has the capacity to comprehensively document and describe the learning and performance needs of CYWD and to establish whether the school environment is able to meet those needs.⁴¹

Figure 2: WHO International Classification of Functioning, Disability and Health (ICF)¹³



Source: World Health Organization.¹³

Within the framework of the ICF (Figure 2), disability is the extent to which impairments in body structures and functions arising from a health condition create challenges for an individual's participation or involvement in important life situations such as the home, school or community.¹³ Participation can be influenced by factors such as child characteristics (health conditions, body functions, and structures) and context (facilitators or barriers) of the physical or social environment.

Participation in everyday activities is therefore seen as the main driver of development that is vital to health and well-being and also the ultimate goal of intervention, i.e. a means and an end.⁴² The traditional medical model, where intervention focuses on remediating discrete discipline-specific physiological or psychological skills at the level of body functions and structures, has shown very little empirical evidence of improved functioning in everyday activities and increased participation in life situations.⁴²

Within both health and education intervention services, the rehabilitation goal for CYWD should be to increase their

participation in life situations. When children and youth receive their main form of intervention in the healthcare setting, rehabilitation professionals from various disciplines need to come together and develop shared or common goals for current as well as future interventions. These goals should aim to facilitate children's participation in life situations that the family/child/youth deem important for development.

The following approach is recommended for rehabilitation professionals to develop and monitor long-term and short-term participation-related goals.^{43,44}

- Use data from discipline-specific assessments and map the results onto the components of the ICF (Table 1). However, many traditional assessments are still quite impairment focused and tend to map mainly onto the body structure and function components of the ICF. For this reason, an increasing number of more authentic tests are being developed that can be mapped on the activity, participation, and environmental factor components of the ICF.⁴¹

Table 1: Assessment data mapped onto components of the ICF

| Health condition: language disorder | | | |
|-------------------------------------|---|--|---|
| Assessment data | Body functions and structures | Activity and participation | Environmental and personal factors |
| | <p>Cognitive functioning</p> <ul style="list-style-type: none"> • Average (KBIT-2). <p>Language skills</p> <ul style="list-style-type: none"> • Morphology (word form) and syntax (sentence structure) - below average (CELF-P2). • Narrative skills - below average (language sample). • Receptive vocabulary - average (PPVT-4). • Expressive vocabulary - average (EVT-2). <p>Speech</p> <ul style="list-style-type: none"> • Articulation - within normal limits (GFTA-3). • Phonological errors (cluster reduction; fronting; HAPP-3). <p>Voice, fluency, hearing</p> <ul style="list-style-type: none"> • Within normal limits. <p>Pre-literacy skills</p> <ul style="list-style-type: none"> • Rhyming - below average (PIPA). | <p>(FOCUS child and caregiver interviews)</p> <ul style="list-style-type: none"> • Johnny has difficulty making friends and being included in other children's games. • He also has difficulty joining in conversation with his peers. • Johnny has difficulty communicating independently with unfamiliar adults. • He also has difficulty telling adults about past events. • Johnny enjoys having family members read to him. | <ul style="list-style-type: none"> • Johnny is 4 years old and attends Head Start preschool. • He enjoys preschool, where he interacts more often with teachers than with peers. • Johnny has access to speech and language services. • He lives with his mother, who has a learning disability, and his grandmother, who has a hearing impairment. • Johnny and his family live in a low socioeconomic neighbourhood. • English is the only language spoken in the home. |

Source: American Speech Language Hearing Association. Functional goal writing using the ICF.⁴³

Table 2: Clinical reasoning questions and ICF components

| Body functions and structures | Activity and participation | Environmental or personal factors |
|--|---|---|
| What impairments most affect function in the current setting or at discharge (if in hospital), based on clinician assessment and the family/child/youth self-report? | What activities are the most important to the family/child/youth in their current or discharge setting? | What environmental/personal characteristics help or hinder participation in activities or situations in the current or discharge setting? |

Source: American Speech Language Hearing Association. Functional goal writing using the ICF.⁴³

Table 3: Writing impairment/skill-based intervention goals versus participation-based goals

| Impairment vs participation-based goal/outcome | |
|--|---|
| <p>Impairment/skill-based</p> <ul style="list-style-type: none"> • Bongani will use gestures to communicate with his mom. • Jaydon will name body parts and favourite toys. | <p>Participation-based</p> <ul style="list-style-type: none"> • Bongani will participate in outside play with his mom by pointing to indicate what he wants to do. • Jaydon will participate in bath time by using words to request bath toys for play and will follow directions to wash hands, toes, and other body parts. |

- Ask specific clinical-reasoning questions (Table 2) in relation to the ‘Body Functions and Structures’, ‘Activity and Participation’ and the ‘Environmental or Personal Factors’ components in the ICF. ‘Activity and Participation’ clinical-reasoning questions allow the intervention team to come up with long-term participation-related goals for the child or youth with disability. Clinical reason questions in the ‘Body Functions and Structures’ and ‘Environmental or Personal Factors’ components, allow intervention teams to develop short-term goals that may affect the ability to accomplish long-term participation-related goals.
- Write the long-term and short-term functional, participation-related goals. The key difference between traditional impairment-focused goals and participation-related goals are that the latter are written and documented with regard to participation, and discipline-specific skills are monitored in the contexts in which they are used, i.e. within routines and activities.⁴⁴ The examples in Table 3 show how each discipline can shape its discipline-specific goals in relation to a common participation-related goal. While the example given is written from the perspective of children who have speech/language impairments, occupational therapy or physiotherapy-related goals would focus on discipline-specific skills needed for participation in the shared or common goal to improve participation in outside play or bath time.
- Monitor and evaluate participation-based goals. In order to know whether a participatory goal has been achieved, it is important to ask parents, teachers,

caregivers or relevant people in the participatory context of the child whether they are participating in a way that meets their expectations.⁴⁴

Similarly, for CYWD in educational contexts who are required to participate in curricular and extracurricular activities, the intervention team consisting of rehabilitation professionals and educators can develop shared education-specific Individual Support Plan goals or curriculum-related participatory goals.

Since the ICF includes more than 1 600 codes, professionals trained in use of the ICF often perceive the classification and coding system to be quite complex. A more pragmatic and practical approach as described above, or use of predetermined core and code sets could increase its utility and accessibility.⁴¹ An ICF core set is a shortlist of selected ICF codes considered most relevant to describe the functioning of a person with a specific health condition or disability, e.g. autism spectrum disorder. A code set is a set of selected categories or codes for specific purposes in different service settings, e.g. a code set for children attending special schools or even particular age groups.⁴¹

The ICF can therefore provide a comprehensive view of functioning and a universal language for interdisciplinary intervention for CYWD. It offers a common framework to structure information on child functioning from a medical, psychological, social, educational and environmental perspective.⁴¹ Given that the knowledge and language used in public health, education, and rehabilitation

professions are diverse, the need for a common language to explain the functioning of children in various intervention environments is paramount.

It is encouraging that undergraduate⁴⁵ and postgraduate¹⁸ inter-professional education programmes in South Africa have started to incorporate training on the ICF into the curricula and training of health and rehabilitation professionals. However, there is a need for continuing education in this area as many professionals still work largely within a medical model.

Conclusion

This chapter explored the intersectoral challenges facing health and education that affect the health, development and academic performance of formal school-aged CYWD. While macrosystemic policies should be clear and specific to CYWD, this is typically not the case. A biopsychosocial framework such as the ICF is recommended. Such a framework aligns with the ethos of existing policies, and can guide and improve collaboration between professionals within and across the health and education sectors. Although this alone may not be enough to solve all the challenges of intersectoral collaboration, it would be a step in the right direction.

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