

STRENGTHENING UNIVERSAL HEALTH COVERAGE THROUGH DISABILITY-INCLUSIVE PRIMARY HEALTH CARE: AN ACTION-ORIENTATED TOOLKIT FOR HEALTH CARE SERVICES

Jill Hanass-Hancock, Thakasile Ndlovu, Nonkulelekho Tesfey, Bradley Carpenter, Samantha Willan, and Kristin Dunkle

BACKGROUND

Achieving Universal Health Coverage (UHC) in South Africa assumes that persons with disabilities can access primary health care (PHC) facilities and services. Access for persons with disabilities is essential in South Africa as persons with disabilities have a 20-year shorter life expectancy than their peers without disabilities. This life expectancy gap is driven by persons with disabilities having increased healthcare-related needs and health risks while also experiencing diverse barriers to healthcare. Barriers to health care include attitudinal, physical, financial, and communication challenges at the healthcare facility level. Facilities may lack elements of universal design and reasonable accommodation of persons with disabilities, have limited training of staff related to disability, and lack adequate linkage to necessary disability and rehabilitation services. Therefore, facility assessments should include a focused assessment on disability inclusion, accessibility, and service delivery. However, facility assessments in South Africa today do not include an appropriate disability accessibility and inclusion assessment tool.

INTERVENTION DESCRIPTION

An action-orientated disability inclusion toolkit for healthcare facilities in South Africa was co-created with healthcare staff and persons with disabilities in two developmental cycles. In cycle one, a disability facility assessment tool was developed to increase awareness of disability accessibility and service delivery gaps in PHS in a simple and action-orientated way.

In cycle two, an intervention menu was created, enabling staff to identify solutions to improve accessibility and inclusion. Each cycle followed five distinct steps of development: a review of needs, design of the tool, consensus discussion to adapt the tool, pilot-testing and adaptation of the tool, and identification of the next steps.

RESULTS

The cyclic consultations, adaptations, and field testing led to the co-creation of a meaningful and feasible toolkit for PHC facilities.

Cycle 1: The initial consultations and pilot testing led to the development of an assessment tool with four sections, namely universal design of health facilities, reasonable accommodation, health care worker training, and care pathway linkages. Universal design and reasonable accommodation were further broken down, giving the tool seven sub-sections. Each sub-section included a set of key elements/questions in a simplified format.

Next, the co-creation process revealed the need to discuss solutions to address gaps. Therefore, the assessment tool includes a two-stage process, with stage one focusing on the facility assessment and stage two focusing on identifying feasible solutions for the facility.

Lastly, the co-creation process led to a paper and digital version of the tool (RedCap); automated, instant facility reports; and easy-to-use training guides and online modules. The automated facility reports provided summary tables, spider diagrams, and overall progress rings. These tools visualized the results, making them easy to understand and enabling the identification of areas needing improvements (figures 1 & 2). The simple design and the automated report enabled laypersons to use the tool after a short training session (later recorded as four online training modules of 15 minutes each).

Cycle 2: The pilot testing of the facility assessment tool revealed that health care workers took significant actions to change their facilities after an assessment. However, staff needed information on how to improve disability accessibility

and inclusion; where to acquire accredited training; and how to improve disability data collection, referrals, and follow-up. Hence, intervention options were needed for each 'key element'. In consultation with representatives from the health and disability sectors, tangible and feasible solutions/interventions were identified, complementing the toolkit with an intervention menu.

The development of the intervention menu also revealed that many solutions are available for the three sub-domains of universal design. These solutions are also described in South African building standards and could be implemented. However, the consultations also revealed that some key elements lacked solutions and needed research and development (figure 3), specifically in the sub-domains of reasonable accommodation (accessible information and disability assistance and support), skills training, and care pathway linkages. In particular, accredited disability-focused courses and accessible information and educational material are needed to prepare PHC staff to provide services to persons with disabilities. The intervention menu development also revealed that solutions are not yet available for disability-inclusive record keeping at clinic level and data capturing. In fact, the clinic records and health information systems do not require disability data collection in intake/patient forms and electronic record-keeping. Without disability data and information, clinic staff do not know when they are working with a person with disabilities, what disability needs they need to accommodate or how to plan for the provision of disability and rehabilitation services (including assistive devices). On a country level, it is impossible to monitor and evaluate service delivery to and the needs of persons with disabilities without having disability data in the information systems.

Figure 1 Example Spider Diagram of a Clinic Assessment for all Seven Sub-sections

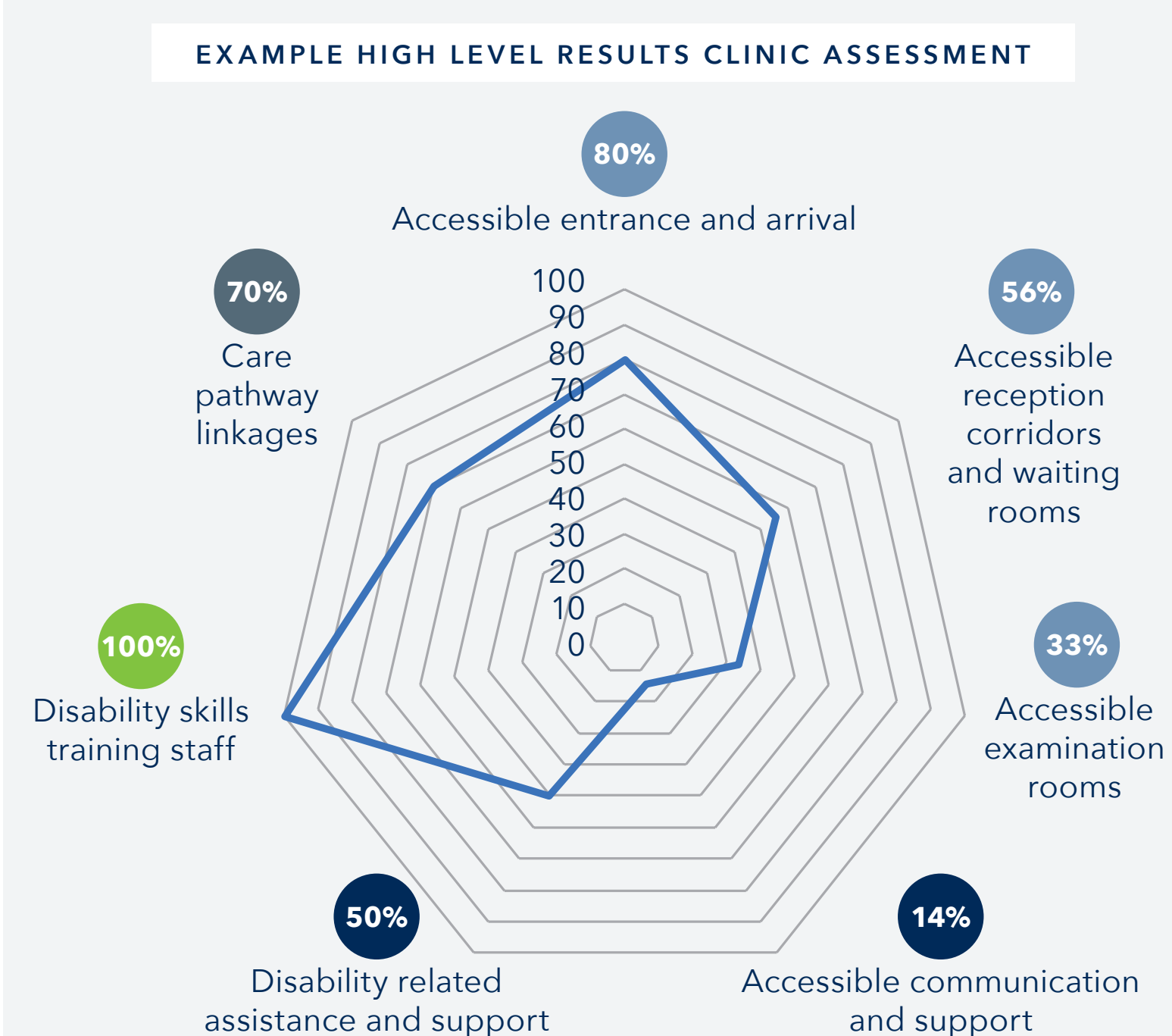


Figure 2 Example Progress Ring Reflecting the overall Disability Inclusion and Accessibility Status of a Clinic

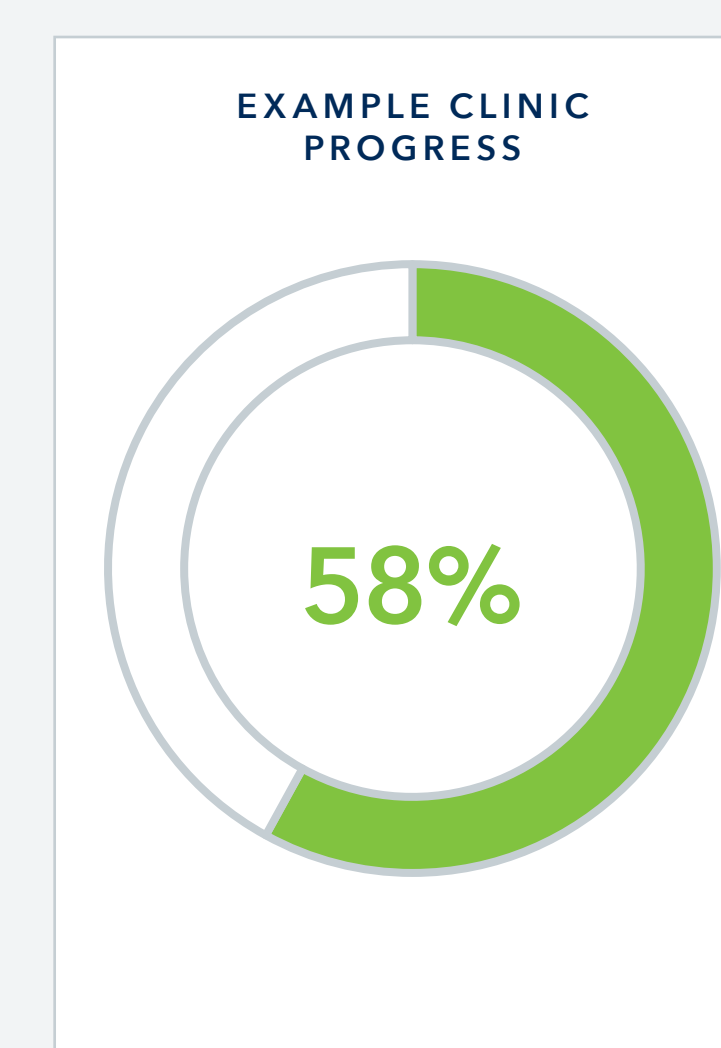
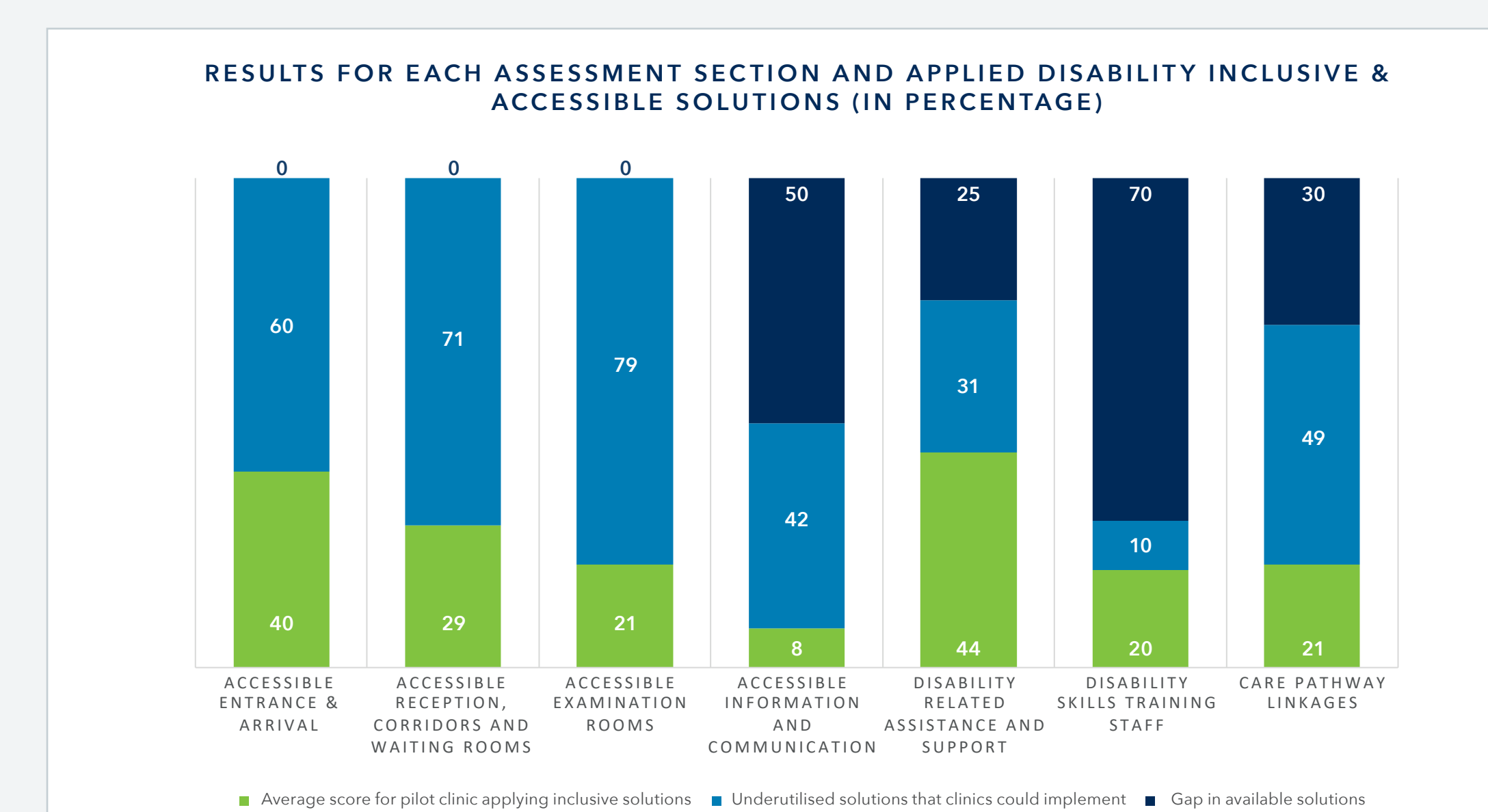


Figure 3 Overview of Implemented (green), Available but not Utilised (blue) and Gap in available (grey) Disability-Inclusive Solutions



LESSONS LEARNT

The cyclic and consultative approach enabled the development of a feasible facility assessment tool and a complementary intervention menu, moving facilities toward UHC for and with persons with disabilities in South Africa. The process revealed that participating clinics only implemented a small portion of available solutions but embraced the idea of improving their facilities. It also revealed that staff needed significant support to identify feasible solutions. Furthermore, some sub-domains do not yet have solutions available in South Africa, and research and development are urgently needed to design solutions. Solutions are most needed in the sub-domains of inclusive and accessible information material, training on different disability needs/issues, and the development of healthcare information systems that capture and utilize disability data to improve service delivery to persons with disabilities.

KEY MESSAGES

UHC requires assessment of and actions towards disability inclusion and accessibility