Beyond Access: Working towards retention in care in rehabilitation services

Implications for service design and progress towards UHC

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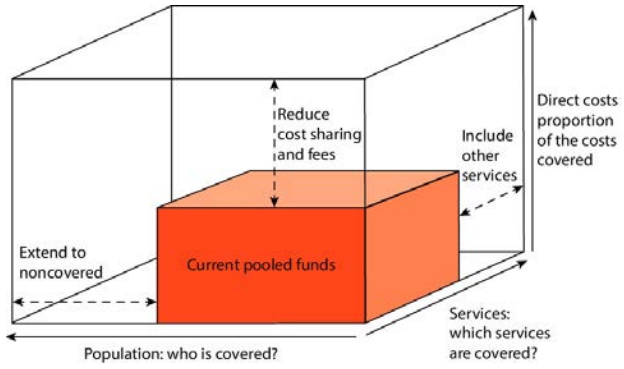
Universal Health Care

'People should be able to access healthcare of sufficient quality to be effective, when and where they need it, without experiencing financial hardship.' *(full range of care)*

Equity in:

- Coverage (NB sub-groups)
- Quality of care
- Financial Risk Protection



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UHC is....

- A financing mechanism
- Incremental
- Country specific e.g.
  - epidemiological profile
  - socioeconomic and demographic profile
  - population demands
  - health systems objectives.....etc.

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However the pooling and purchasing...

Stewardship

Service design and delivery:

- Impacts heavily on affordability, acceptability and accessibility
- Relies heavily on health information systems (or should)
- Should inform contracting
- Will affect supply/demand curve including in market shaping exercises around assistive devices
- Affects uptake and retention in care
- Affects outcomes and impact of these reforms

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Why the emphasis on monitoring and evaluation.....

- What is our baseline?
- Where are the gaps?
- What are our explicit objectives?
- What gives us the best bang for our buck (benefits package)?
- Are we getting bang for buck? (contracting, investments made)
- Is it equitable across sub-groups?
- What progress are we making towards UHC?

And at grass roots- how well are we performing for service x, who do we need to see and at what frequency for services x, y and z, who is waiting for what device, do we need more staff, what is our lost to follow up rate?

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Monitoring UHC

Two discreet components measured:

1. Coverage (with focus on equity)
2. Financial Risk Protection

Measured using a combination of

1. National census and surveys
2. Routinely collected health data (DHIS)

How far can we disaggregate???

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Rehabilitation Services in Africa

Insufficient information for budgeting and planning purposes

Spending on rehab largely OOP (FFS/coverage gap)

Poor understanding of rehab and disability issues at all levels

Majority rehab services centralized/institution based

Poor integration of D&R into policy and planning

Critical HR skills shortage

Rehab at PHC level virtually non-existent

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What makes rehabilitation unique?

- Hidden population
- Historically underfunded and poorly developed service
- Nature of rehab is on individual goal selection and need for multiple visits
- Impact of systemic inequities, environment, community and family attitudes and context on decision making and outcomes
- High levels of poverty, comorbidities and case complexities- strong need for coordination of care
- Case outcomes often require work across sectors- not confined to diagnosis and medical model approach
- Ingredients approach does not work

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Persons with disabilities are understood broadly to experience:

- The same general health needs as others, but with far greater barriers to accessing and remaining in basic healthcare;
- Additional specific health needs relating to their disability (e.g., psychotropic medication for mental illness, assistive devices, targeted rehabilitation interventions); and
- Higher risk of additional health conditions developing

(World Health Organization & World Bank, 2011)

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Barriers to uptake and retention in care

Demand side barriers

-financial (incl transport)
- environmental
- attitudinal
- acceptability of care
- quality of care
- consistency of care
- beliefs
- appropriateness of intervention

Supply side barriers

- HR: including HRD, skills mix and trans-disciplinary work
- budget & supply chain
- information management
- governance and leadership
- service design

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Sadly, with service design & delivery....

- It's not as simple as preventing impoverishment
- It's not as simple as addressing HR
- It's not as simple as ensuring geographical coverage of services
- It's not as simple as simply ensuring assistive devices are adequately funded
- It's not as simple as providing 'evidence based health sector interventions' according to stipulated guidelines

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Financial Risk Protection:

How significant is the cost of transport for people with moderate-severe disabilities in low resource settings?

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Data gap/assumption	Impact on % cohort experiencing CHE
Welfare grant income used as total household income	**Over-estimation (**subsistence farming, piece jobs, actual employment may incr. income- why consumption is usually used but no data)
Welfare grants shared equally amongst household	**Underestimation** (not all family members contribute equally to the 'pot')
Unable to estimate food expenditure or consumption	**Under-estimation** (this would reduce total amount available for additional things like transport)
Used transport cost as a major contributor towards healthcare expenditure, as all healthcare for PwD is free at point of care if they meet the means test- yet despite this, the level of centralization of a rehab service appears to have huge impact on uptake and retention in care.	**Over-estimation**, if using traditional definitions which exclude transport as part of healthcare expenditure
Additional costs such as productivity time lost/ loss of earnings/ additional costs of hiring a caregiver/task shifting not taken into account- no data	**Under-estimation** (this would increase cost of accessing healthcare)
Assumption that each clinical visit was effective and needed and of sufficient quality	May change if the onus is on the family to seek healthcare, even if all financial outlays equal (acceptability of care, perceived need)
Absence/infrequence of certain services (orthopedics, plastics, orthotics) reduce referrals and utilization rates	**Under-estimation** of need. If need realized, this would lead to increased OOPE.
Small sample size (80 households)	**Under or Over estimation**
Model only runs for 8 months	**Under-estimation**, as clients allocated to monthly, three monthly or six monthly visits according to severity of CP and age, as per Manguzi package of care
Lack of stratification of results (geographical location, quintiles etc)	Less insight into factors affecting equity in access

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Rough estimation of different models of care

Threshold for CHE	5%	10%	15%	20%	25%	30%	35%	40%
Current model	8%	8%	6%	4%	4%	4%	4%	4%
Clinic model	38%	18%	14%	10%	9%	6%	5%	5%
Centralized hospital model	65%	49%	40%	26%	16%	14%	11%	8%

South Africa's CHE is estimated at a mere 1.4% at the 10% threshold

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Beware of current assumptions....

- ''Placing the responsibility on the patient to get themselves to the point of care in a low resource setting is reasonable''
- ''Everyone with need of the service has equal means of reaching it, especially at PHC level''
- ''Outreach to clinic level is sufficient''
- ''Free health care for people with disabilities, with a welfare grant, is sufficient for equity in access''

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Take home points:

- Transport is a major driver of OOPE in accessing health for people with disabilities- even more so than those without- in low resource settings
- Access to, expenditure on and capacity to pay differs across families and is not directly proportional to distance from health facility.
- Poverty, disability and unmet need are entwined. More attention to sub-group analysis is required.
- This requires improvements in health information systems including population surveys and routine rehab data
- Formal quantitative research is required

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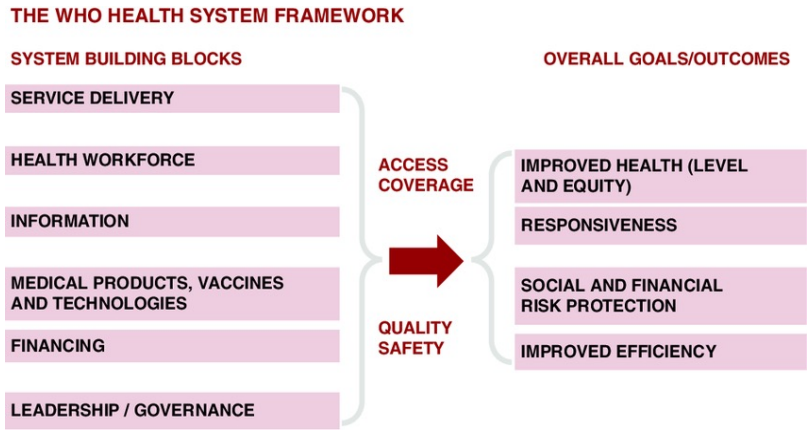
Equity, Efficiency and Effectiveness



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Decentralizing certain services to home level

- Address governance issues
- Explicit priority setting
- Amalgamation of separate patient databases
- Development of electronic patient management system
- Task sharing, role release
- Strengthened end user involvement in service delivery
- Diversified funding
- Effectiveness: SDH and social context more visible

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Indicators : Cerebral palsy program 0-17 years	2018 0 - 18yr	2021 0-18 yrs	2018 0-5yrs	2021: 0-5yrs	2018 6-12yr	2021 6-12yrs	2018 13-17yrs	2021 13-17yrs
Number children: CP 0-18y	136	133	53	46	51	43	33	30
General rehabilitation program statistics: Cerebral Palsy services								
Seen for follow up rehab in last 6 months	61	113	31	36	22	40	7	26
Coverage rate: eceived at least on session in the last 6 months	45%	85%	58%	78%	43%	93%	21%	87%
Average number of rehab sessions received in last 6 months	2	4	1.3	6	0.7	4	0.5	3.7
Total number OPD/clinic sessions in 6 months	116	145	68	76	35	26	11	14
Total number home visit sessions in 6 months	14	518	No data	141	No data	161	No data	96
Average number rehabilitation home visits offered per month for cohort	2	86		24		27		16
Wheelchair and seating services: cerebral palsy								
Total eligible for seating device	104	141	34	35	30	38	21	26
Total received seating device	70	131	11	29	22	36	19	26
Seating coverage rate	67%	93%	32%	83%	73%	95%	90%	100 %
Seating review rate: one follow up review in last year	33%	81%	0%	80%	17%	84%	50%	88%
Seating review rate: 2 follow ups reviews in last year	10%	65%	0%	64%	0%	76%	17%	60%
Average age at receiving first seating	12	10	4.4	2.1	7.5	6.5	11.5	10.6

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Supporting factors

- Priority setting- identifying vulnerable groups (vertical equity)
- FRP: Decentralizing care to community level
- Improvements in data management
- Improvements in governance and coordination of care
- Strengthening end-user involvement in service delivery
- Visibility: home/community context, need to work inter-sectorally
- Diversify funding

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Beware of current assumptions....

- ''The cost of getting there is justified by the outcomes of the service received‘’
- ‘’decentralizing to clinic level is sufficient for quality and access to care’’
- ''Monitoring rehab utilization rates in absence of sub-group analysis is sufficient''
- ''Monitoring assistive device issuing rate is sufficient as a proxy for access to care’’
- ‘’to do more we need more…’’

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Beyond the bubble:

The best medical intervention is but naught if you have failed to address the wider issues

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Confined by a Health Perspective

- Significant historical social context
- Discharged home, lost to follow up
- Brought back into care, donations acquired, block therapy initiated, discharged back home with full support
- Nothing changed! Regressed to baseline
- Addressed documentation & welfare
- With income came status and family support
- 6 months later improved function back to block therapy discharge levels

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Lessons learned

- There are prerequisites which need to be in place before gains in rehab can be realized
- The best rehabilitation interventions are a waste of time if the family is not on board.
- Home affairs and welfare applications can be out of the financial reach of many
- A CBR approach and working inter-sectorally is essential. Confining yourself to Health will not give you the outcomes.
- In a low resource setting, a rehab worker may be IT. HR skills mix for rehab is essential
- Without information systems and active tracing this client would have been lost forever

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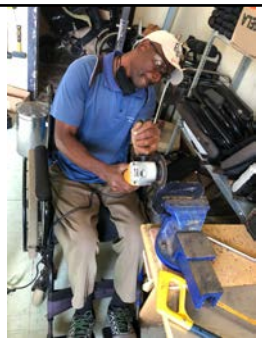

Review, Repair, Refurbish, Reissue, Repurpose!

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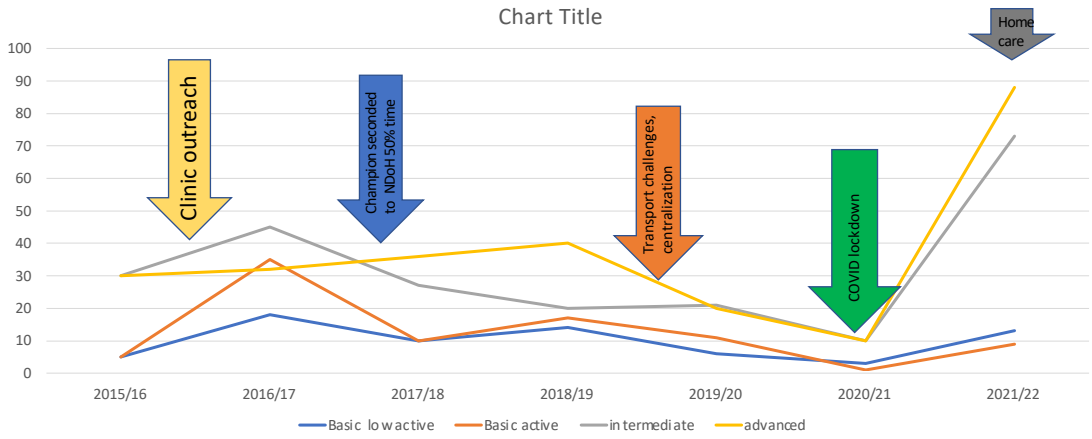
Effects of resources & levels of decentralization on wheelchair seating review follow ups for different categories of user



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Lessons learned

- Access to rehabilitation services means more than the first consultation
- **Retention in care** for those with moderate and severe disabilities very **sensitive to changes in resources, decentralization and coordination** of care
- **Different strategies for follow up** seem to work for different categories of user, but **active surveillance** is key
- **Tracking retention in care is a valuable tool in measuring program performance** (wheelchair issuing rate remained fairly constant throughout this period)
- **Diversify funding- chairs, spares, tools, vehicles.**
- Repair, refurbish, reissue (**pool approach**) to meet demand

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At country level

Insufficient workforce planning

Singing the same song? Have we built allies outside rehab?

Emphasis on preventative and curative care, focus on mortality data

Notoriously poor intersectoral collaboration (SDH)

Fragmentation of financing for rehabilitation

Poor integration of D&R into platforms and programs

Supply chain & infrastructural challenges

Fragmentation of D&R services across platforms, areas and types of care

Low levels of national coordination of D&R services

Poor coordination of care at program and individual level

Low levels health systems research, few contextualized CPGs

If D&R data exists: rudimentary, prevents sub-group analysis

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