



An international perspective on the future of care and clinical research in autism: The Lancet Commission's December 2021 report

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Future of care and clinical research in autism



- Three in person meetings including two conferences about international approaches to autism.
- Committees outlined sections and presented outlines and possible recommendations at second meeting. Revisions and reviews by committee members and full committee.
- Draft formally reviewed by three reviewers outside the committee.
- Revised, then reviewed by Lancet.
- “Launched” by Lancet in December; hard copies available in spring.

Future of care and clinical research in autism: urgent call for change



- Members from six continents, thirteen disciplines and thirty-two people, including autistic people and parents of autistic people
- Our first point is urgency: It is time to directly address ways of improving the lives of the 78 million autistic people in the world and their families
- There is much evidence and scientific data known about autism that is ready to be used...
- Particularly if we can determine what strategies and interventions and support systems benefit whom, when and with what intensity (as well as how)



- Autism is a neurobiological condition
 - Basic and translational science efforts are important (and well funded)
 - The clinical challenges autism raises for society and for autistic people are not ones likely to be solved by biomedical solutions for most people in the near future
- We have focused on recommendations that can be put into effect in the next 5 years
 - Targeted research can change lives now by improving mental and physical health and strengthening support systems
 - To have immediate and long-term effects on the quality of life for autistic people and their families
- Research that will result in immediate improvements in the lives of autistic people and their families should be prioritised by governments and funding agencies worldwide

Autism is a heterogeneous condition (a “spectrum”)



- Autism manifests differently *between* individuals
 - Some autistic people can live independent lives; others need support every day throughout their lives; and many others fall in between
- Autism also manifests differently *within* individual across the lifespan
 - It is a developmental condition
 - Autistic people will require different intervention and supports at different points in their lives
- Valuing autism and neurodiversity benefits society as a whole

Adding a priority for large scale research with immediate implications



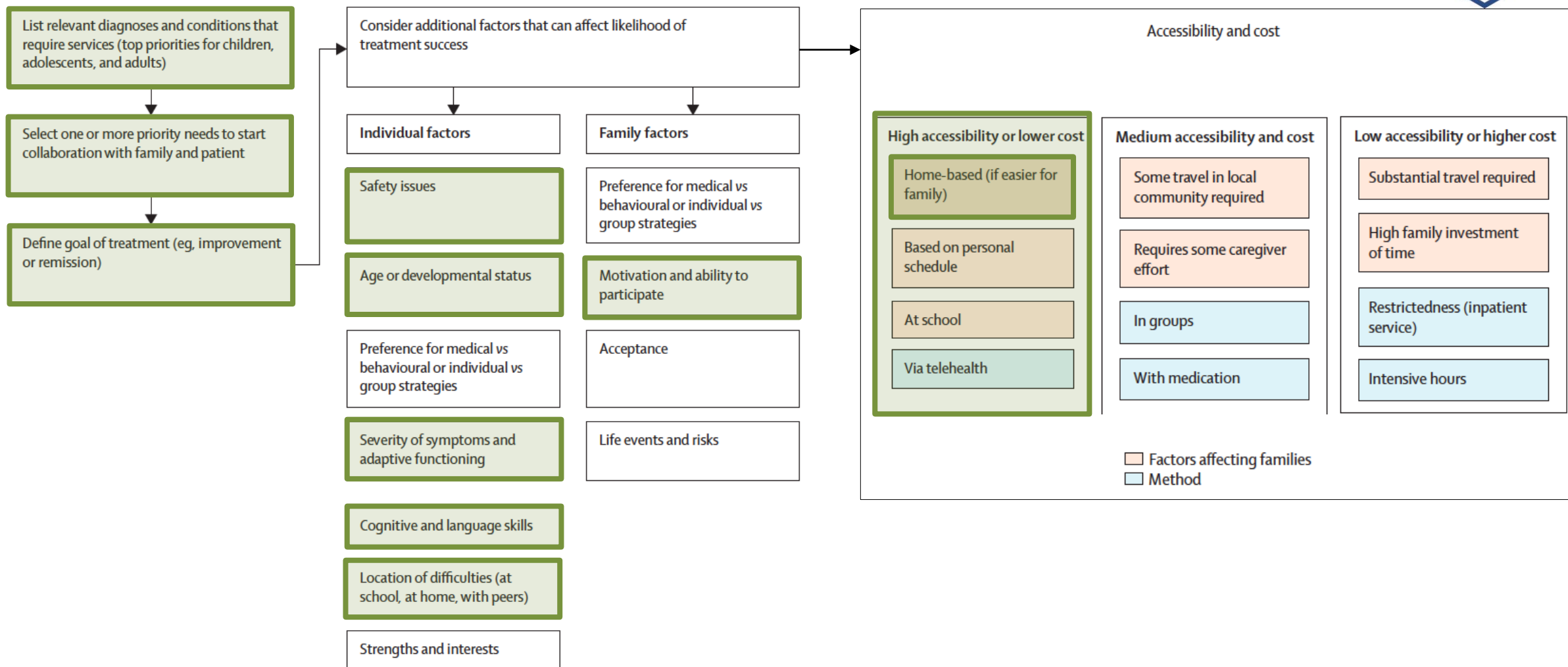
- However, this will require different research on a much larger scale and coordination across arms of government and services to find results that are meaningful on an individual level.
- Such information can also provide the beginnings for culturally appropriate adaptations across the globe using the strengths and addressing the needs of different communities.
- Much of this information, and other research, also has the potential for direct bearing to approaches to other developmental disorders and mental health conditions.

A stepped care, personalised health model for autism

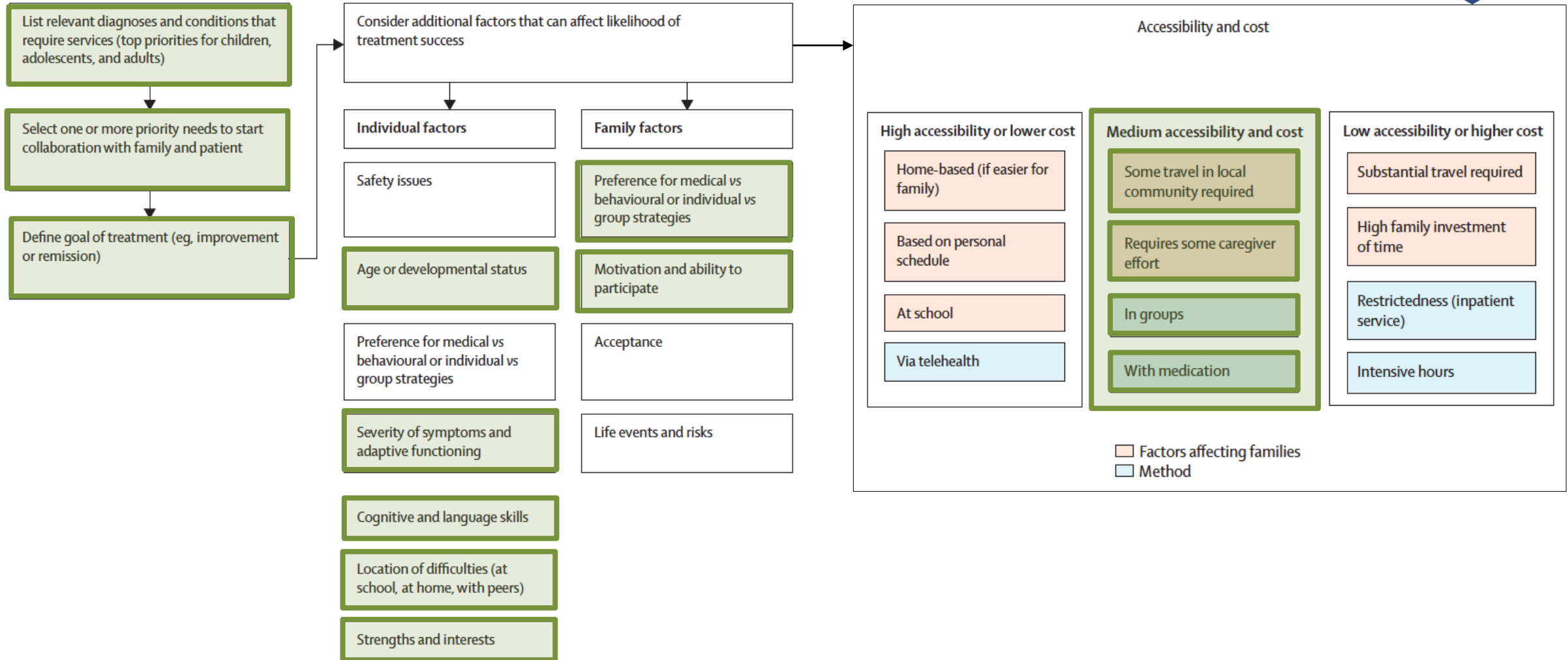


- We propose to shift the traditional stepped care perspective and propose steps that take into account the costs, burden and preferences of individuals or families (rather than just to the health system) and personalization on the basis of the autistic individual and families' needs, strengths and challenges.
- This means that information needs to be gathered about the skills and needs of each autistic person and their family, beyond a diagnosis to include other factors and preferences....
- This is more than “person-centered.”
- And updated as needed because it will change as children become adults and as adults grow older.

Stepped care example – minimally verbal 5 year old in LMIC



Stepped care example – 15 year old with social anxiety in HIC





- Existing service systems may not be designed to meet the specific needs of autistic individuals or are underfunded
 - Service deserts exist for many groups, especially those living in LMICs or impoverished neighborhoods in HICs
- Service user is a lifelong social role for many autistic individuals

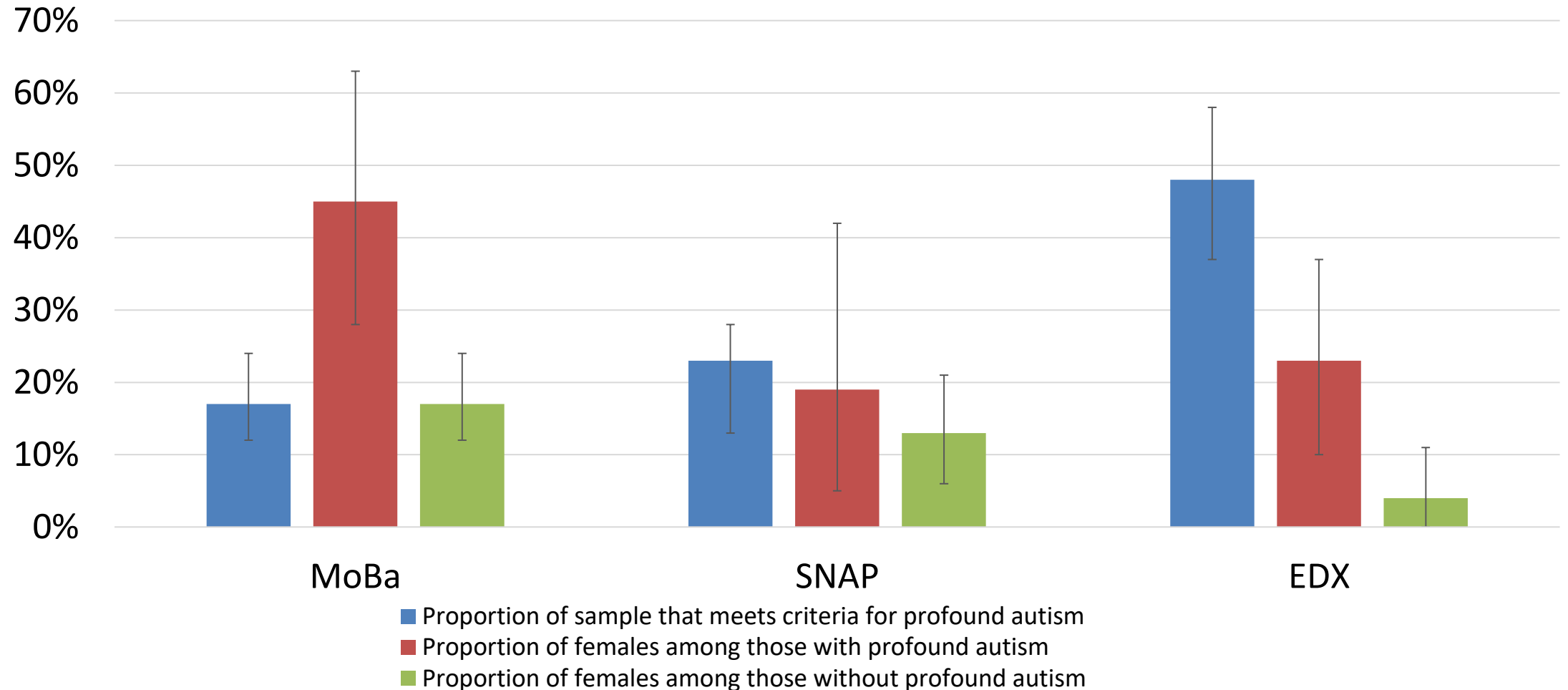
95% of children
under age 5 with
developmental
disabilities live in
LMICs

We propose the concept of profound autism as an administrative term

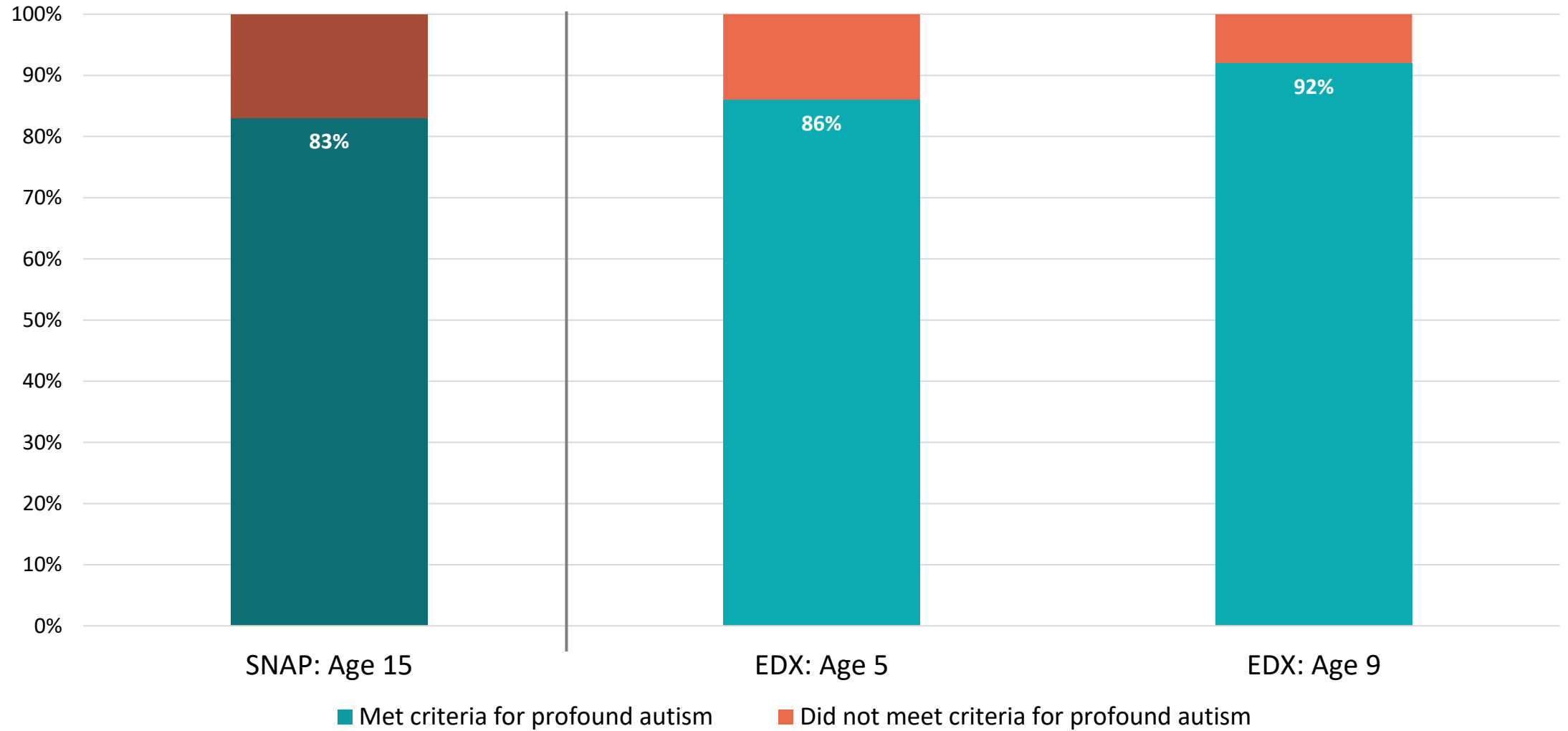


- To highlight the needs of autistic people with severe intellectual and communication disabilities with profound needs for care and support
 - Those who cannot speak for themselves and need extensive care throughout their lives
 - Require 24-hour access to an adult who can care for them if concerns arise
 - Not be able to take care of basic adaptive daily needs
- Individuals with substantial intellectual disability or very limited language (or both)
 - Most have complex co-occurring difficulties e.g., self-injury, epilepsy, aggression
 - Appropriate to identify from mid-childhood or later when future needs are clear
- New analysis of data from 3 cohorts – 2 population (MoBA, SNAP), 1 clinical (EDX)
 - Proportion meeting criteria for profound autism ranged from 18% to 48%
- Intended to spur the clinical and research communities to prioritise the needs of this vulnerable and underserved group of autistic individuals

Profound Autism in Three Samples



Stability of profound autism across time in those who met criteria in adulthood



A message of hope and potential for change

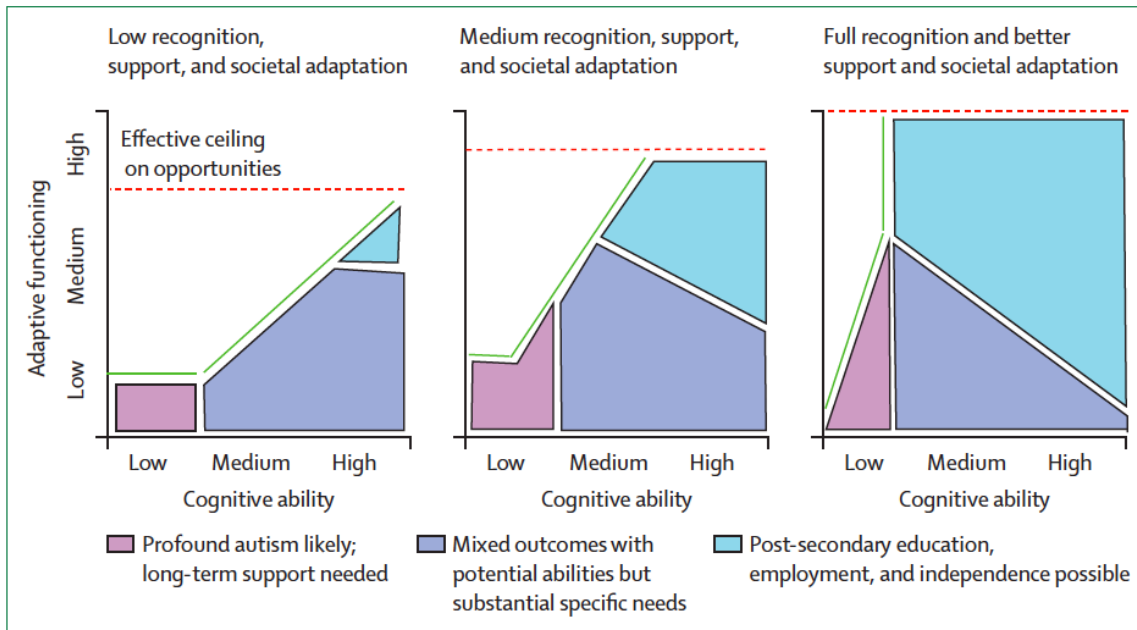


Figure 4: Societal response and services can optimise outcomes for all people with autism
The green line indicates the hypothetical degree to which the environment supports the adaptive potential of autistic people with different cognitive abilities.

- In the end, this is a message of hope.
- We know much about what autism is, how it differs across individuals and how we can support development in autistic people – though we have not put this information to practice as much as we need to.
- We know about the potential for change and ways to make this happen.
- We can also extend much of what we have learned and will learn to other developmental disorders and mental health conditions.
- Let's work together and do this now.