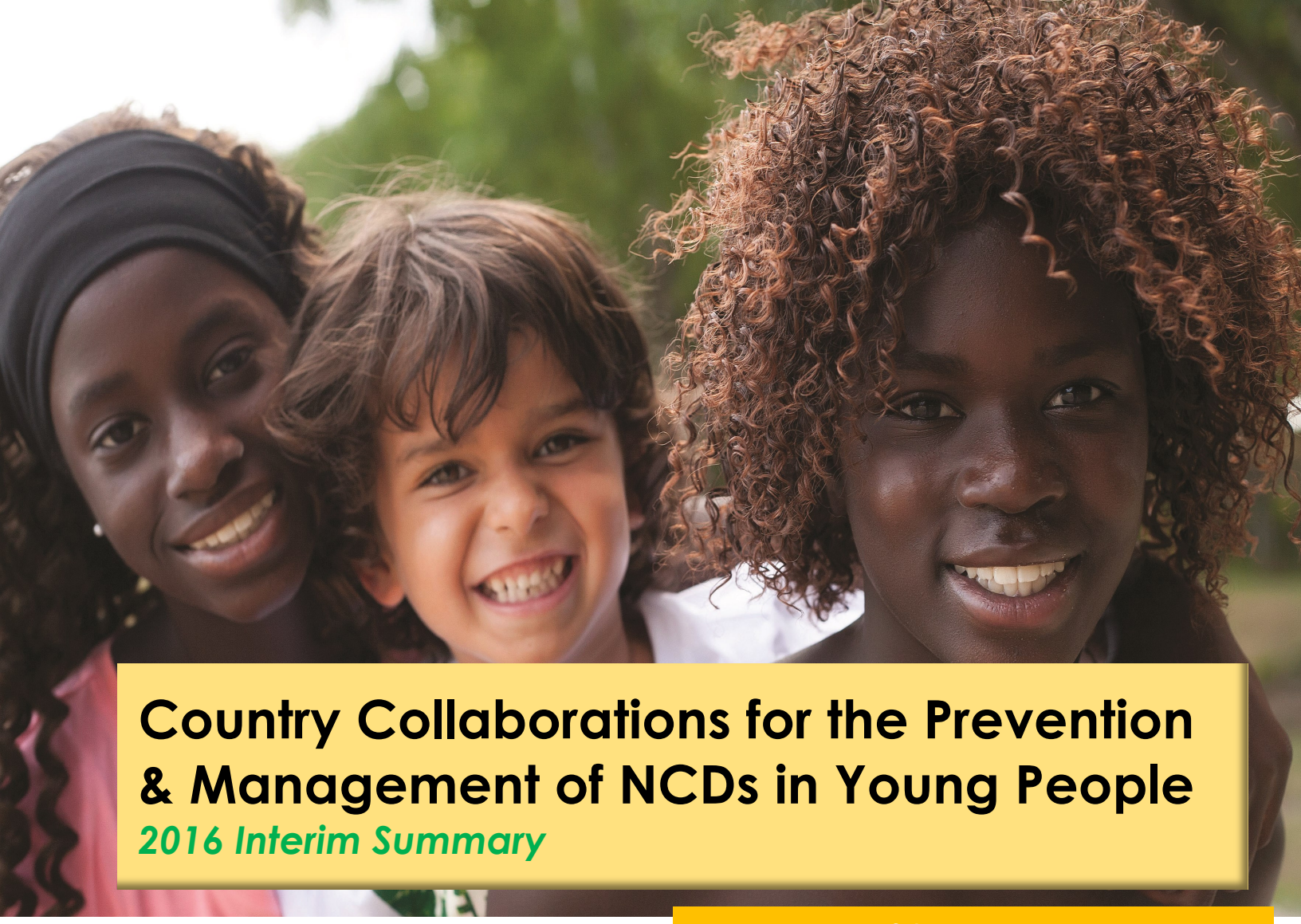


Country Collaborations for the Prevention & Management of NCDs in Young People

2016 Interim Summary

Millions of children and adolescents live with or are affected by non-communicable diseases (NCDs)

NCDs are non-infectious diseases that cannot be spread person-to-person, such as cancer, cardiovascular disease, diabetes, asthma, and mental disorders[1]. In 2012, NCDs were responsible for 38 million deaths – 40% of which were premature deaths[2]. Traditionally seen as only an issue in adulthood, NCDs can occur or begin in childhood. Furthermore, 70% of preventable adult deaths from NCDs are linked to risk factors starting in adolescence[3]. Therefore, children and adolescents represent the 'age of opportunity' for both prevention and management of NCDs.

A plan for action against NCDs

In 2013, the World Health Organization (WHO) endorsed the Global Action Plan[5] for the Prevention & Control of NCDs to address the rising burden of NCDs globally. The goal of the action plan is to reduce the preventable and avoidable burden of morbidity, mortality and disability due to NCDs by means of multi-sectoral collaboration and cooperation at national, regional and global levels, so populations reach the highest attainable standards of health and productivity at every age and NCDs are no longer a barrier to well-being or socioeconomic development.

NCDs and Youth[3, 4]

- Globally, 25% of children are stunted, 6.5% are overweight or obese, and 1 in 4 obese adolescents have signs of type 2 diabetes
- Many children with cancer live in areas without adequate pediatric care, causing disparities in survival
- 90% of the 1 million children born each year with congenital heart disease live in areas without adequate medical care
- Globally, 100,000 young people start smoking each day; more than 90% of adults who smoke, started as children or adolescents
- Second-hand tobacco smoke exposure causes asthma, otitis media and respiratory infections in children
- Mental health disorders, motor vehicle trauma, homicide, and suicide cause major morbidity & mortality in children and youth

NCD CHILD

Putting Children and Adolescents on the Global Non-Communicable Disease Agenda

This publication is online at www.ncdchild.org

The Sustainable Development Goals

The United Nations' Sustainable Development Goals (SDGs) were launched at a summit of the UN General Assembly in September 2015 and represent both a framework and a call to action to end extreme poverty and expand equitable development universally. The 17 goals apply equally to all countries and are meant to galvanize collective action from 2015 through 2030. **Goal 3, "Ensure healthy lives and promote well-being for all at all ages,"** builds on the unfinished agenda of the Millennium Development Goals and adds ambitious new targets. In the year since their adoption, the focus has shifted to country-level implementation of the goals.

As outlined in the plan, the objectives needed to reach this goal include:

1. Raising the priority given to prevention and control of NCDs in global, regional and national agendas and internationally agreed development goals, through strengthened international cooperation and advocacy
2. Strengthening national capacity, leadership, governance, multi-sectoral action and partnerships to accelerate country response for the prevention and control of NCDs
3. Reducing modifiable risk factors for NCDs and underlying social determinants through creation of health-promoting environments
4. Strengthening and orienting health systems to address the prevention and control of NCDs and their underlying social determinants through people-centered primary health care and universal health coverage
5. Promoting and supporting national capacity for high-quality research and development for the prevention and control of NCDs
6. Monitoring the trends and determinants of NCDs and evaluating progress in their prevention and control

Complementing the Global Action Plan and spearheaded by UN Secretary-General Ban Ki-moon, Every Woman Every Child[6] is a multi-stakeholder movement that recognizes all partners — including governments, philanthropic organizations, multilateral institutions, civil society, business, health professionals and academia — have an essential role to play in improving women's and children's health and well-being.

The movement puts into action the UN Secretary-General's updated Global Strategy for Women's, Children's, and Adolescents' Health[3] as a roadmap for implementing the SDG targets to end the preventable deaths of women, children, and adolescents by 2030 and improve their overall health and well-being in order to survive, thrive, and transform. The strategy specifically highlights the key role child and adolescent health challenges play in meeting the SDGs.

NCDs and advocacy in action through NCD Child

Together with the American Academy of Pediatrics (AAP), CLAN, and its governing board, NCD Child has committed to the prevention and treatment of NCDs in children and adolescents by promoting interventions that extend from birth through adulthood. This life-course approach guarantees a continuum of care, treatment, and support for all who are living with or at risk for NCDs. To ensure the rights and health of young people are accounted for in national NCD plans, NCD Child launched a series of regional workshops to engage and connect pediatricians, other civil society groups, young advocates, and government as champions for inclusion of children and young people in NCD plans. This series is part of NCD Child's commitment to the UN Secretary General's Every Woman Every Child[6] movement, and aims to contribute to meeting the objectives of the Global NCD Action Plan and the Global Strategy for Women's, Children's, and Adolescents' Health.

This publication is an interim report on the model of the workshops and current advocacy projects on-going as a result of the workshops to date. A final report will be available when all regional trainings and advocacy projects are complete.

"The biggest opportunity during the next 15 years and beyond is to make adolescents the human face of the SDGs…they are a key target group for many of the SDGs." ***Lancet commission on adolescent health and wellbeing***

Goals and objectives of regional NCD workshops

Each workshop had the same goal - to provide an environment to create and support country-level teams consisting of clinicians, government officials, civil society organizations, and young leaders that will collaboratively address the NCD agenda affecting children and young people in their country - with the long term outcome to increase dialogue and policy change resulting in specific attention to the needs of children and young people living with or at risk for NCDs. Our objectives, anticipated outputs, and outcomes are shown in Graphic 1.

The workshop model: engaging diverse champions

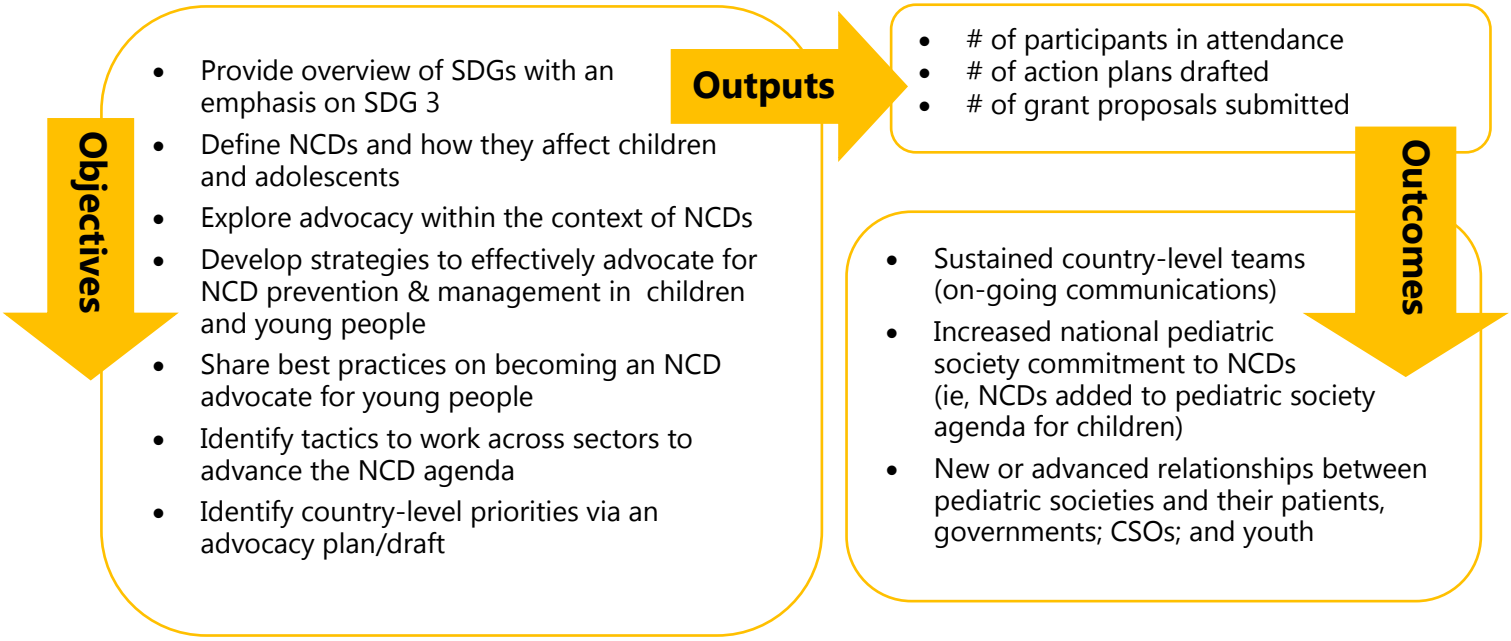
The workshops linked with national and regional pediatric society meetings, to specifically engage child and adolescent health leaders. Adding pediatric leaders' voices to those of other civil society groups, government, young people, and families living with NCDs helps bring about effective advocacy for health and social system responses to the challenges of NCD prevention and treatment for all. Outreach to government (Ministries of Health), multilateral organizations (WHO, UNICEF), other non-governmental organizations (e.g., NCD Alliance), and to community-based groups (e.g., Youth Banner) helped to recruit participants and model multidisciplinary, multi-sector collaboration by engaging diverse participants in speaking roles during the workshops. This resulted in a diverse and robust engagement of child and adolescent health champions and regional collaborators. It also supported greater country ownership and regional stakeholder buy-in for country-led advocacy activities.

Participants were recruited through national pediatric societies, existing local NCD advocacy networks, and global organizations, including from the NCD Alliance and UNICEF. Ideal candidates had a strong interest in the topic, some background to advocacy, and were nominated by and engaged within professional networks committed to participating in follow-up plans and sharing of information.

Health care providers, specifically pediatricians, were identified as the primary participants in the workshops because of their role as natural advocates. As trusted, credible technical health experts, pediatricians are an untapped advocacy resource in many countries. They can offer expertise and practical examples of children, adolescents, and youth who they have supported and treated. By harnessing their knowledge and experiences, pediatricians have potential to advocate beyond their clinics.

Effective policy-related advocacy requires an appreciation of global standards of WHO, the financing mechanisms which support health systems, and the policy makers who ultimately decide how countries' health systems will operate. Civil society, private sector, and adolescent/youth health advocates may understand many of these influencing factors but are neglecting to engage their countries' child health providers and professionals. Pediatricians, on the other hand, may have an extensive knowledge of the "why?" change is needed, but a more limited familiarity of the "how?" change can be implemented at scale. By bringing the different groups together, NCD Child endeavored to close these communication gaps – focusing on country team advocates with a commonly held goal that through varied experiences, pediatricians, civil society, and young people can mobilize and influence policymakers more effectively.

Graphic 1: Workshop Training Model



NCD Child designed the one and a half to two day workshops based on previous successful advocacy training models[7] from AAP. Initially, a faculty planning group was convened for each region to build the curriculum. The planning group included NCD Child Governing Council members, AAP experts in advocacy, and local representation from a regional pediatric society when possible. Sessions were designed to empower participants to be actively engaged in their country's NCD agendas. They included a mix of key presentations, interactive panels, small group discussions, and planning for national action. The program addressed a global overview of the state of NCDs in children, adolescents, and young people from UNICEF and WHO regional leaders, introduction to advocacy, and practical strategies for planning and implementing effective advocacy.

Developing a curriculum for such a diverse group, albeit, with a common goal, required an appreciation of different learning styles. The program needed to address priorities of multiple stakeholders, including clinicians, government officials, non-government advocates, and young people from different countries and backgrounds. The workshop was designed to be learner-centered where faculty primarily served as facilitators and coaches for teams of participants who were experts in their own country's needs and systems. This approach balanced active adult learning needs while still providing both content and examples for visual learners who prefer presentations, graphs, and lectures.

Recognizing that participants' knowledge about clinical issues of national significance and their interest in the global agenda to address NCDs varied, the curriculum intentionally linked local health concerns to the global NCD agenda. Both didactic presentations and panels were followed by Q&A sessions to address participant comprehension and to allow for sharing attendee real-life case studies and expertise. An emphasis on knowledge sharing from facilitator to participant; participant to facilitator; and participant to participant was the basis for the active learning sessions.

"Nothing about us, without us." This declaration from a young training attendee is a perfect example of why young people must be part of the conversation. NCD Child's core principles emphasize the need to work for and with young people. At least one young adult from the NCD Child Governing Council served on the planning committee for each workshop. These individuals helped to develop and finalize curriculum, identify regional youth networks, and serve as primary faculty. They each brought their own experiences, expertise, and networks to the table during the planning phase.

The recruitment of young advocates to attend the workshops evolved throughout the four trainings. The process was most effective during the East Africa training. The youth representative on the planning group managed recruitment – through existing networks of NCD Child and other key stakeholders. The growing relationships between NCD Child and the International Federation of Medical Students Associations, Young Health Program, Young Professionals Chronic Disease Network, and others allowed for a strong showing of young advocates at this workshop as both participants and speakers. The youth cohort also received 'remote' pre-workshop mentoring to help set expectations and roles during and after the training. We suspect youth recruitment will continue to improve in future workshops as NCD Child cultivates existing and new partners.

"Young people are the world's greatest untapped resource. Adolescents can be a key driving force in building a future of dignity for all."

Ban Ki-moon, Secretary-General of the United Nations

NOTHING ABOUT US, WITHOUT US.

Building an advocacy in action plan

The crux of the workshop was the completion of an advocacy plan by country teams. Its goal was to help participants recognize the multiple steps involved in advocacy – going from an appreciation of a 'need' to a full-fledged strategy which addresses the identified need. The template was developed after a review of existing models from the AAP, WHO, and others.

Three major components are included in the plan: prioritization of needs; goals, objectives, and associated activities; and stakeholder analysis. The curriculum lectures and breakout sessions followed the model of the advocacy plan, and during the breakout sessions, teams worked together on the corresponding section of the plan. At the end of the workshop, each participant or country team presented their initial drafts and received feedback from the faculty and peers.

The advocacy plan template was tweaked after the initial workshop; the breakout sessions revealed a lack of full understanding of the tool. It was simplified with clearer guidance and added examples. Prioritization also required additional support as participants requested to receive materials in advance to allow time for preparation or identification of key issues in their respective countries.

To develop additional critical thinking skills, specifically root cause analysis[8], a Fishbone analysis and the 5 Whys' techniques[9] were introduced in the second workshop. The Fishbone or Ishikawa technique drills down to the causes of a specific problem. It is helpful in identifying confounding variables which may influence the overall effect. The 5 Whys' analysis, in practice, is somewhat elementary; however, it has the potential to identify several factors or causes of an issue that may have not been previously considered. It can take three to five 'whys' or more to identify a root cause.

Both tools were introduced by lecture and put into practice through discussion and as advocacy plans were developed.

Making an advocacy case to policymakers was another topic that evolved after each workshop. Familiarity with presenting and advocating to government officials on behalf of children and adolescents varied in the diverse group of trainees. To facilitate practice, the development of elevator speeches was introduced in the third training. Going a step further, during the most recent training, participants were asked to create an advertisement of their respective societies' or organizations, which identified a need and how their "service" or "product" addressed it. The creative exercise early on in the workshop allowed participants to get to know each other through the development of the ad and presenting the solution to the group.

An advocacy plan template served as the practical framework during each workshop.

<u>The plan addressed:</u>

- Prioritizing major NCD issues in the country
- Setting plan goal and SMART (see figure) objectives
- Associating activities, barriers, timeline, and indicators of success with each objective
- Defining stakeholders, noting both decision-makers and influencers
- Reviewing and modifying full plan to address any gaps

The champion network

As of September 2016, four regional workshops have been hosted in Peru, India, Kenya, and Canada. The goal is to host a minimum of one workshop in each of the six WHO regions: African (AFRO), Americas (PAHO), South-East Asia (SEARO), European (EURO), Eastern Mediterranean (EMRO), and Western Pacific (WPRO). Given the Academy's close relationship with several pediatric societies in the aforementioned regions, the workshops were also planned to coincide with regional society congresses.

For example, in Lima, Peru, the workshop was held prior to the Latin American Congress of Pediatrics which covers 25 countries across South, Central, and North America. In Latin America, where more than a quarter of all of adults (18+) are obese, participants prioritized the marketing of unhealthy foods and sugar-sweetened beverages[10].

Graphic 2: Country Coverage in all Workshops

The subsequent training in Hyderabad, India, preceded the Asia Pacific Congress of Pediatrics; membership within the Asia Pacific Pediatric Association spans through several countries in SEARO, EMRO, and WPRO. In India, the priority areas were less homogenous and went beyond the four major risk factors. In fact, many of the participants questioned WHO on their categorizations, noting the numerous conditions which fall outside of cardiovascular disease, cancer, tobacco, and diabetes.

During the East Africa workshop, held in Eldoret, Kenya before the Kenya Pediatric Association annual meeting which normally brings in multiple East African pediatric societies, we achieved a recruitment milestone with a more balanced participant breakdown of civil society, several young people, WHO, and national Ministry of Health.

The most recent workshop, in August 2016, was hosted prior to the International Congress of Pediatrics, making specific regional recruitment a challenge. Instead, industrialized, high income countries were primarily targeted with a goal of assessing the nation's role within its boundaries and its contribution to the global agenda.

Table 1: Champion Participants in each Regional Workshop

Region/Focus	**Participant breakdown**			
	Civil Society Organizations	Young People	Ministry of Health	UNICEF / WHO
Latin America November 2015	✓	×	✓	✓
Asia Pacific January 2016	✓	✓	×	✓
East Africa April 2016	✓	✓	✓	✓
Industrialized August 2016	✓	✓	✓	✓

Putting the plans into practice

To help motivate the champions to continue their advocacy beyond the workshop, a small grant opportunity was presented at the end of each training. A request for proposals was issued and all participants were invited to submit proposals on behalf of a country team. Proposals were reviewed by the faculty of each workshop. Feedback was given to each proposal and technical advisors from the faculty group were assigned to each grantee. The funding was considered seed money to ensure pediatricians, civil society, government, and young people continue talking about NCDs, learning about NCDs, and working to prevent NCDs in their respective countries. A summary of awards is in Table 2.

An additional ten grants are still under review by faculty or are being revised by the grantee. These grants are from participants in India, Malaysia, Sudan, Malawi, Burundi, Tanzania, Kenya, and Ethiopia. Topics addressed include nutrition, tobacco prevention, diabetes, physical activity, and cancer prevention and management. Grantees continue to work with their technical advisors as they plan, execute, and monitor their advocacy plans.

Table 2: Summary of Country Advocacy in Action Plans

Country	Project Goal
Argentina	Establish a **network of instructors** who are trained in preventing, detecting, and dealing with overweight and **obesity** in children and adolescents at the primary care level
Mexico	Decrease morbidity and mortality of children due to exposure to **tobacco** smoke and to **accidents and injuries** through leadership training of pediatricians
Bangladesh	Increase awareness across sectors and among stakeholders of inter-relationship between NCDs, **nutrition**, and **obesity** to reduce the burden of NCDs in children and adults in Bangladesh
Indonesia	Improve adolescents' knowledge, attitude, and behavior towards **obesity** and its impact in adulthood via school seminars in Indonesia
Japan	Improve **nutritional** status of children living with NCDs and decrease length of stay in hospitals by training nutritional specialists
Malaysia	Reduce prevalence of **rheumatic heart disease** in Malaysia (1) Host an **NCD workshop** consisting of clinicians, government officials, CSOs, and young leaders who collaboratively address the NCD agenda affecting children and youth in Malaysia (2)
Myanmar	Disseminate knowledge of NCDs to pediatricians and allied medical professionals, specifically regarding **obesity**, **diabetes mellitus**, **disability**, and **mental health**
Nepal	Educate practitioners and other healthcare workers on **disaster preparedness** as an emerging child health issue in NCDs to better serve children of Nepal across all age groups
Pakistan	Ensure children **living with disabilities** in Pakistan have access to comprehensive rehabilitation services
India	Strengthen the efforts towards **obesity** reduction and NCD prevention in line with India's adopted NCD targets, by engaging pediatricians in India and enabling schools to adopt health promoting policies and activities
Ethiopia	Increase the level of awareness on **road traffic accidents** to children and their parents using contextually appropriate and acceptable means to influence behavior
Uganda	Tackle childhood **obesity** by raising awareness of importance of physical activities in schools (targeting teachers and students)

CASE STUDY: *Reducing road traffic accidents in Ethiopia*

The Ethiopian Pediatric Society (EPS) will focus its post-training advocacy efforts on increasing awareness on road traffic accidents to children and their parents. Globally, road traffic injuries are the leading cause of death in adolescents[11]. The World Health Organization estimates a fatality rate of 25.3 per 100,000 with a seat-belt wearing rate of under one percent of all occupants[12]. A national action plan is needed to stimulate a coordinated effort to reduce preventable death and disability related to road traffic accidents. A key component to any successful strategic plan and priority activity is raising the current levels of awareness on both current incidence and strategies for prevention. In collaboration with the regional education bureau, local traffic police, school officials, representatives from the Ministry of Health, and youth ambassadors, EPS will develop educational curriculum with corresponding IEC (information, education, and communication) resources for both students and parents. The program will be evaluated through pre- and post-surveys and by number of resources distributed. EPS will aim to present the results at their annual meeting and disseminate the resources.

Learning from the past; improving for the future

After each workshop, the planning group came together to assess what worked well and what needed to improve for the next region. Evaluation comments were integrated into the following curriculum when possible.

A shared comment across the workshops was how the session left participants with practical, actionable next steps. The breakout activities were also well-received as time to think through objectives while also having the opportunity to get real-time feedback from peers and faculty. The feedback also influences future training's curricula and resources; materials were distributed ahead of the workshop, additional country resources were shared; and additional time was allotted to the breakout sessions. A youth advocate from the East Africa training remarked "The workshop was an amazing networking platform. I hope to engage the other attendees especially the youth advocates as mentors to the youth I work with in Nairobi." Others commented on some of the more practical insights – including a type of root-cause analysis. A medical student from India specifically cited the value of the fish-bone analysis and how he actively uses this technique in his classes.

While the trainings were based on a proven model, adaptation proved to be a challenge at times. Identifying faculty who were familiar with the advocacy training model, experts in NCD prevention and management, and completely bilingual was difficult. Simultaneous interpretation helped ensure all participants were able to understand the presentations; however small breakout groups were less successful.

Other limitations included the duration of the workshop – many participants suggested allowing additional time. The ideal workshop would include representatives from a country's pediatric society, ministry of health, civil society, and youth advocates. Early on, it became evident this model was not possible for all countries. The focus changed to ensuring all workshops had representation from each of the stakeholder groups, regardless of country. While youth engagement and participation improved, future trainings will require additional attention and recruitment for this stakeholder group.

The way forward

The workshop outcomes are sustained country-level teams; increased national pediatric society commitment to NCDs (ie, NCDs added to pediatric society agenda for children); and new or advanced relationships between pediatric societies and their patients, governments; CSOs; and youth. It will take additional time and commitment to attain these results, but the stage has been set. NCD Child plans to monitor the work of the country teams and facilitate learning and the exchange of experiences between the teams. The network of more than 124 champions from over 40 countries have much to do back in their countries to engage local and national stakeholders, and have the chance to advance beyond national borders to the global agenda to promote the rights and needs of children, adolescents, and young people. Discussions for workshops in Europe and the Middle East are on-going for 2017.

"Interactions with doctors, participants, and workshop facilitators helped me modify my approach to NCDs and build a stronger platform"
Workshop Participant

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NCD Child is a global coalition of organizations and individuals focused on non-communicable diseases in children, adolescents, and young people. The main goals of NCD Child are to advocate for inclusion of children, adolescents, and young people in the global NCD agenda; promote both treatment and prevention for addressing the NCD burden; and support inclusion of youth and family voices in the global and country planning for NCDs.

NCD CHILD
Putting Children and Adolescents on the Global Non-Communicable Disease Agenda

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