The Future of Para Report Cards on Physical Activity of Children and Adolescents With Disabilities—A Global Call for Engagement, Data, and Advocacy

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The Active Healthy Kids Global Alliance (AHKGA) is an international not-for-profit organization of researchers, health professionals, and stakeholders working together to advance the physical activity of children and adolescents around the world. Established in 2014, the AHKGA has a vision of a world of active, healthy kids. The AHKGA is committed to powering the global movement to get kids moving through thought leadership, knowledge translation/exchange and mobilization, capacity building, and advocacy, facilitated by sustainable partnerships and cross-sectoral collaborations that enable best practice exchanges, networking, and cross-fertilization. The dominant effort of the AHKGA has been the Global Matrix initiative (Aubert et al., 2022; Tremblay et al., 2022). The Global Matrix initiative involves the collaboration of multiple countries/jurisdictions working together to produce Report Cards on the physical activity of children and adolescents. The initiative follows a harmonized process that allows for comparability, cross-fertilization of ideas to improve the grades, global networking, and the compilation of international data across a series of indicators related to the physical activity of children and adolescents. To date, >70 countries/jurisdictions have produced Report Cards based on the harmonized process, and 68 countries/jurisdictions have
participated in at least one Global Matrix. The AHKGA is interested in, and attentive to, principles of justice, equity, diversity, and inclusion (JEDI; Tremblay et al., 2022). The AHKGA encouraged Report Card teams participating in the Global Matrix 4.0 to present data on inequalities in their Report Cards (i.e., by age, gender, disability status, cultural/ethnic/racial identity, socioeconomic status, urban/rural status). Out of the 159 Report Cards from the four Global Matrices combined, 124 (78%) included stratified data for at least one JEDI area; 13 (8%) reported at least some data in relation to disability status. The Report Card indicators for Overall Physical Activity, Sedentary Behavior, and Organized Sport and Physical Activity had the most extensive inclusion of JEDI information. Gender breakdowns were the most reported with 115/159 (72%) Report Cards, followed by rural–urban, socioeconomic, disability, cultural differences, and sexual orientation breakdowns with 49 (31%), 24 (15%), 12 (8%), nine (6%), and three (2%) out of the 159 Report Cards reporting these areas, respectively. Overall, Canada, the United States, New Zealand, Finland, and Ireland emerged as the top five countries with respect to reporting JEDI data. These countries have consistently reported JEDI data in their Report Cards across multiple indicators and JEDI areas. Report Card teams participating in the Global Matrix 4.0 were invited to report physical activity information disaggregated by disability status (as well as gender, age, area of residence) in a survey to enhance the Global Matrix 4.0 findings (Silva et al., 2022). More details on the AHKGA and the Global Matrix initiative are available on our website (www.activehealthykids.org) and elsewhere (Tremblay et al., 2022).

Throughout the development of Global Matrices 1.0–4.0, there has always been an interest and intent to include children and adolescents with a disability (CAWD). However, the effort was rather passive and demonstrably ineffective. For example, countries/jurisdictions included at least some information related to CAWD in Global Matrices 1.0 (0/15; 0%), 2.0 (2/38; 5%), 3.0 (3/49; 6%), and 4.0 (8/57; 14%). The Netherlands (Burghard et al., 2018) and Hong Kong (Sit et al., 2020) developed, released, and published separate Report Cards focusing specifically on this underrepresented group. In the lead up to the release of the Global Matrix 4.0 in October 2022, an effort was initiated by the International Federation for Adapted Physical Activity (IFAPA) to capitalize on the Global Matrix 4.0 country connections to explore more deliberately and more intensively the physical activity behaviors and opportunities for CAWD. This effort was harmonized with and endorsed by the AHKGA but was a separate and independent initiative. The effort resulted in the development of a Global Matrix of Para Report Cards (Ng et al., 2023), separate from the AHKGA Global Matrix 4.0. A special issue of Adapted Physical Activity Quarterly was devoted to the findings from 14 participating countries/jurisdictions (https://journals.humankinetics.com/view/journals/apaq/40/3/apaq.40.issue-3.xml). The AHKGA supported the Para Report Cards by promoting the effort to AHKGA members, negotiating a symposium and dedicated poster area for the Para Report Card initiative at the 2022 International Society for Physical Activity and Health Congress, providing a free open access publication in the special Global Matrix 4.0 series hosted in the Journal of Physical Activity and Health (Sit et al., 2022), and offering guidance and mentoring on the Global Matrix/Report Card development methodology.
The Para Report Card initiative was a major contribution to the global knowledge of physical activity for CAWD, where 14 participating countries/jurisdictions followed harmonized but adapted procedures from the Global Matrix 4.0 to grade the same 10 physical activity indicators. This allowed useful international comparisons (Ng et al., 2023) and also illustrated the scale of the global problems of both physical activity levels and physical activity surveillance in CAWD. Even among those 14 countries/jurisdictions with Para Report Cards, 45% of the Report Card indicators could not be graded as there was insufficient evidence (Ng et al., 2023), and 11/14 (79%) countries/jurisdictions were able to grade the key indicator of Overall Physical Activity for CAWD. Overall, the Para Report Cards presented higher grades for the sources of influence indicators (School, Family and Peers, Community and Environment, and Government) than the behavioral indicator grades (Overall Physical Activity, Active Play, Organized Sport and Physical Activity, Active Transportation, and Sedentary Behavior), and the behavioral grades were generally lower than those reported in the AHKGA Report Cards from the Global Matrix 4.0 (Ng et al., 2023). The Para Report Cards initiative showed low levels of physical activity among CAWD, with an average grade for the Overall Physical Activity indicator of D- indicating that less than one third of CAWD were estimated to meet the guideline for moderate- to vigorous-intensity physical activity (Ng et al., 2023). In countries/jurisdictions participating in the Global Matrix, which have been able to grade indicators for both the general population of children and adolescents and CAWD, behavioral grades for CAWD are typically much lower. The U.S. 2022 Report Card provides a clear example of the disparity (Physical Activity Alliance, 2022). In countries/jurisdictions that have been unable to grade for CAWD, the problem is effectively invisible. The Para Report Card initiative also highlighted the urgent need for improved measurement instruments tailored to CAWD and targeted efforts for data collection (Ng et al., 2023).

AHKGA Evaluation of the Para Report Card Initiative

Following the completion of the Para Report Card initiative, the AHKGA invited Para Report Card leaders/co-leaders from the 14 participating countries/jurisdictions along with the AHKGA and IFAPA leadership representatives to complete an evaluation survey to reflect on their experiences with the development of Para Report Cards and provide suggestions for the future. The evaluation survey was completed by 70% \( (n=16, \text{ representing 13 countries/jurisdictions and both organizations}) \) of targeted respondents \( (n=23) \). According to survey results, the main challenges during the Para Report Card development and participation in the initiative were related to data gathering (e.g., limited national surveillance evidence on CAWD), inconsistency of definitions, grade assignment process (e.g., limited suitability of certain indicators/benchmarks for CAWD), and project leadership/management (e.g., tight timelines, limited communication, decision-making processes). The main successes reported by Para Report Card leaders included establishing a national group of researchers in the adapted physical activity field and collaboration with the national Report Card team, expanding professional
networks internationally, producing an evidence-based national assessment of the status of physical activity of CAWD using the AHKGA framework allowing for international comparisons, publishing scientific papers, and attracting media attention to the status of physical activity of CAWD. In some countries/jurisdictions, the production and knowledge dissemination of the Para Report Cards has already resulted in some fruitful discussions with community organizations (e.g., sports clubs, sports charities) and government (e.g., disability advisory groups, Public Health Agency, National Committee for Health). Survey participants highlighted that the findings from the Para Report Card initiative provide useful baseline information on the status of physical activity of CAWD at national and international levels, highlight the lack of inclusion/representation of CAWD in public health surveillance, and emphasize the need to work toward improving this in the future.

Overall, 94.8% (15/16) of evaluation survey respondents expressed interest in reporting physical activity data of CAWD again; however, most thought a different approach would have advantages. Moving forward, the majority (82%, 13/16) would prefer an integrated approach (i.e., every country participating in the AHKGA’s Global Matrix 5.0 includes the best available physical activity data on CAWD in their national Report Card) rather than a segregated approach (i.e., development of Para Report Cards as an independent initiative, as was done in 2022) (13%, 2/16).

AHKGA Planning Survey for CAWD

In August 2023, the AHKGA also conducted a planning survey to collect opinions of AHKGA network members regarding the integration or segregation of data on CAWD into/from the Global Matrix 5.0. The survey was distributed to AHKGA e-newsletter subscribers (i.e., past and potential future Report Card team leaders and members, n = 209 from 90 countries/jurisdictions) and was completed by 38% (n = 79, representing 55 countries/jurisdictions) of network members. The preference for the integrated approach among the AHKGA network members found via the planning survey (Figure 1) echoed the results of the Para Report Card leaders’ evaluation survey described above. However, 42% (33/79) of the planning survey participants were “unconfident”/“very unconfident” in the availability of any data related to Report Card indicators for CAWD in their country, versus 38% (30/79) and 20% (16/79) of respondents who were “confident”/“very confident” and “neither confident nor unconfident,” respectively. Better involvement of researchers and leaders from the adapted physical activity sector in integrated country Report Card development may help unearth evidence and improve confidence.

Where to From Here?

The AHKGA did not lead the Para Report Card initiative nor was involved in its decision making. However, an official partnership between AHKGA and IFAPA came into effect on September 1, 2022, when the groundwork for the Global
Matrix 4.0 and the Para Report Cards was already completed. The release of the 2022 Para Report Cards on Physical Activity of Children and Adolescents With Disabilities and the related Special Issue of *Adapted Physical Activity Quarterly* has no doubt increased awareness, advanced understanding, and hopefully propelled forward research and advocacy in the area. Given that this has always been an area of interest to the AHKGA, and an official partnership with IFAPA is in place, plans for the Global Matrix 5.0 (for release in October 2026) in relation to inclusion of CAWD have recently evolved.

In an effort to maximize impact, and with guidance from the surveys summarized above, AHKGA Board discussions and correspondence from Para Matrix 4.0 and the Para Report Cards was already completed. The release of the 2022 Para Report Cards on Physical Activity of Children and Adolescents With Disabilities and the related Special Issue of *Adapted Physical Activity Quarterly* has no doubt increased awareness, advanced understanding, and hopefully propelled forward research and advocacy in the area. Given that this has always been an area of interest to the AHKGA, and an official partnership with IFAPA is in place, plans for the Global Matrix 5.0 (for release in October 2026) in relation to inclusion of CAWD have recently evolved.

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Figure 1 — Response summary from the AHKGA network collected via AHKGA’s Global Matrix 5.0 planning survey (August 2023) concerning possible approaches to reporting data on the physical activity of CAWD. AHKGA = Active Healthy Kids Global Alliance; CAWD = children and adolescents with a disability.
Report Card participants, and to take advantage of our formal partnership with IFAPA, for the Global Matrix 5.0, the AHKGA plans to (a) create a standing committee devoted to JEDI whose Chair will become a member of the AHKGA Board of Directors; (b) appoint Dr. Cindy Sit, President of IFAPA to Chair the newly established JEDI Committee and join the AHKGA Board; (c) proactively and prospectively integrate JEDI and equity-deserving groups (including CAWD) into all of the planning for the Global Matrix 5.0 from the very beginning, even before registrations begin; (d) seek out best practice examples to be highlighted in the Global Matrix 5.0; and (e) plan a manuscript from the Global Matrix 5.0 that focuses specifically on CAWD. Ultimately, we hope to maximize engagement, data collection, and advocacy in relation to CAWD within the Global Matrix 5.0.

Research on physical activity in people living with disability typically lags behind physical activity research in the general population (e.g., generally less representative samples, lower statistical power for population-level data, limited stratification of data for diverse impairment types), and most data on physical activity in people living with a disability have been collected in high-income countries (Martin Ginis et al., 2021). The 2020 World Health Organization Physical Activity Guideline Development Group reported that more research was needed on people living with disability across all ages and encouraged the recruitment of people with disabilities into large “mainstream” studies to increase the generalizability of findings (DiPietro et al., 2020).

The surveillance of physical activity in CAWD is affected by several issues challenging the international consistency and comparability of physical activity and disability measures across surveys and surveillance systems (Martin Ginis et al., 2021). Definitions of disability vary across sectors and countries/jurisdictions so for comparability, efforts to harmonize measures and agree upon operational definitions and terminology are needed. Furthermore, the self-report instruments used to derive international physical activity estimates have little validity and reliability data for populations with disabilities including CAWD (Martin Ginis et al., 2021). Even if data are valid and reliable, in many countries, sample sizes in surveillance systems are too small to provide meaningful surveillance of CAWD and/or results are not disaggregated and reported so that CAWD are effectively invisible to surveillance.

The 2022 Global Matrix of Para Report Cards on Physical Activity of Children and Adolescents With Disabilities (Ng et al., 2023) provided a substantial leap forward for raising awareness about gaps in research, services, opportunities, and policies for this underserved population. Going forward, the AHKGA and IFAPA plan to build off this momentum. The preparations for the Global Matrix 5.0 have already begun with a target of 75 countries/jurisdictions. Registrations for returning and new participants will open in January 2024, and the release event will potentially be held in conjunction with the International Society for Physical Activity and Health Congress (Mexico City, Mexico) in October 2026. As a start, through this commentary, we challenge all researchers studying physical activity among CAWD in all participating Global Matrix countries/jurisdictions to engage with Report Card leaders to unearth, report, interpret, and discuss findings in relation to CAWD in Report Cards.
A Global Call for Engagement, Data, and Advocacy

Physical Activity of Children and Adolescents with a Disability (CAWD)

Enhance surveillance

Disseminate the findings and advocate

Report/grade data on CAWD

Search for data on CAWD

Improve physical activity and health among CAWD
References


