

Building Capacity

Patient Centered Outcomes Research/ Clinical Effectiveness Research (PCOR/CER) for University-Based Programs which Promote Health Improvements for Adults with Intellectual Disabilities. (UPAID)

A partnership between the University of Louisville, University of Georgia, University of Rhode Island, University of Texas, University of Pennsylvania, University of Pacific.

Research has shown that actively engaging patients, caregivers, and other stakeholders in the research process is important because it improves outcomes which are relevant to the patients themselves. Numerous studies in the general population have demonstrated health benefits of regular physical exercise (1) and a few studies have shown that this may also be true for persons with intellectual disabilities (2-4). However there appear to be many barriers to achieving the practice of meaningful regular physical exercise for these medically underserved adults with ID, and this leads to obesity and greater risk for many health conditions such as diabetes, heart disease, mental and behavioral problems, cancer, poor oral health, and worse outcomes for COVID-19 infection. For this reason, UPAID was formed to facilitate engagement of adults with intellectual disability in PCOR/CER, designed initially to determine the most effective ways to engage adults with Intellectual Disability in participation of “meaningful” (*i.e., exercise that leads to increased heart rate*) regular physical exercise.

Initial Purpose of UPAID

1. Improve health outcomes of adults with intellectual disabilities
2. Identify methods to engage adults with Intellectual Disabilities in health promotion, starting with regular physical exercise.
3. Educate other health professionals and students regarding importance of regular physical exercise for adults with intellectual disabilities and how to engage them in the process.
4. Expand membership in UPAID to include all 50 States in the USA.
5. Following the lead of Pediatrics, begin to take steps to develop nationally certified university-based fellowship-level training programs in adult intellectual disability medicine and dentistry.
6. Address the 5 *Priorities* of the Patient Centered Outcomes Research Institute (below a-e):
 - a. Assessment of Prevention, Diagnosis, and Treatment Options:** Comparing the effectiveness and safety of alternative prevention, diagnosis, and treatment options to see which ones work best for different people with a particular health problem.
 - b. Improving Healthcare Systems:** Comparing health system–level approaches to improving access, supporting patient self-care, innovative use of health information technology, coordinating care for complex conditions, and deploying workforce effectively.
 - c. Communication and Dissemination Research:** Comparing approaches to providing comparative effectiveness research information, empowering people to ask for and use the information, and supporting shared decision making between patients and their providers
 - d. Addressing Disparities:** Identifying potential differences in prevention, diagnosis, or treatment effectiveness, or preferred clinical outcomes across patient populations and the healthcare required to achieve best outcomes in each population.
 - e. Accelerating Patient-Centered Outcomes Research and Methodological Research:** Improving the nation’s capacity to conduct patient-centered outcomes research, by building data infrastructure, improving analytic methods, and training researchers, patients, and other stakeholders to participate in this research.

Building Capacity

Initial Methods to Accomplish These Goals

A multi stakeholder workgroup consisting of representatives from different states will be formed in early 2022. Initially, bimonthly zoom conferences will be held to brainstorm and share information that will promote engagement of adults in PCOR/CER and establishment of outcomes that will be measured. Continued Zoom meetings of UPAID and expansion of membership to include other states will lead to a sustainable organization to support PCOR/CER focused on improvement of health of adults with Intellectual Disabilities.

Examples of areas for PCOR/CER that could be promoted by UPAID, other than promotion of meaningful physical activity, include treatments of maladaptive behavior, osteoporosis, seizures, motor dysfunction and periodontal diseases.

By including patients, caregivers, clinicians, and researchers in its membership, UPAID will promote quality relationships between researchers, clinicians, patients, and other organizations which have a shared interest in identifying person-centered methods to improve many health outcomes of adults with intellectual disabilities which can lead to an improved quality of life for this Medically Underserved Population (MUP).

Lastly, while UPAID is focused on adults with Intellectual Disabilities, it will be important for UPAID to collaborate with Pediatricians who treat children with Intellectual Disabilities, autism, and other developmental disabilities, so that “*Transition*” from childhood to adult health services can be improved.

References

1. Lancet Editorial, A Sporting Chance: Physical Activity as Part of Everyday Life. ***Lancet*** 2021, 398, 365. **(See Attached)**
2. Asonitou K., et al, Effects of an Adapted Physical Activity Program on Physical Fitness of Adults with Intellectual Disabilities, ***Advances in Physical Education***, 2018, 8, 321-336.
3. Carmeli E., et al. Can physical training have an effect on well-being in adults with mild intellectual disability? ***Mechanisms of Ageing and Development***, 2005, 126, 299–304.
4. Halle J, et al. Effects of a Peer-Mediated Aerobic Conditioning Program on Fitness Levels of Youth with Mental Retardation: Two Systematic Replications. ***Mental Retardation***, 1999, 37, 435-48.

A sporting chance: physical activity as part of everyday life

Sport is bringing some much needed joy to the world. The Olympics and Paralympics, the Copa América, the European Football Championship, and Wimbledon are bringing excitement to millions after postponement or cancellation in 2020 (safety concerns notwithstanding). Although watching elite sport might be more stimulating than addressing modern day sedentarism, a third *Lancet* Series published this week, following on from publications in 2012 and 2016, shows the importance of regular physical activity and sport to health and wellbeing. The COVID-19 pandemic and the response to it have further amplified the value of being physically active in ways that could benefit individuals and society more broadly.

Since 2001, there has been no improvement in global levels of physical activity. More than a quarter (1.4 billion) of the world's adult population were physically inactive in 2016, putting them at risk of non-communicable diseases (NCDs) and premature mortality. This Series re-emphasises the urgent need to increase population levels of physical activity, with adolescents and people living with disabilities among the least likely populations to receive the support needed to meet WHO's physical activity guidelines.

However, the past decade has seen some progress. In 2018, WHO published the first global action plan for physical activity, providing an evidence-based policy framework for its promotion, with strong links to achieving the Sustainable Development Goals, and a global target to reduce physical inactivity by 15% by 2030. Health benefits from physical activity are now acknowledged to include improvements in mental health, dementia, cognitive health, sleep, and preventing falls and fall-related injuries. Furthermore, physical activity is now recommended in secondary and tertiary prevention of NCDs, especially cancer, to improve quality of life and survival. The co-benefits of physical activity promotion such as improved air quality and climate change mitigation are now widely recognised. The rationale for action has widened to include non-health sectors.

Disappointingly, policy implementation and scale-up of effective physical activity interventions have been insufficient and uneven, in part, some experts say, due to changes in the way the Global Burden of Disease project assesses risk factors. Uptake of a multisectoral approach to physical activity has been slow because it requires

cross-government collaboration and a substantial investment outside health system budgets. Compared with high-income countries, levels of physical activity are still far lower in low-income and middle-income countries, where the need is greater. Surveillance of physical activity remains patchy and, worryingly, it stopped during the pandemic in many parts of the world and has now left a gap in trend data.

Restrictions during the pandemic have probably decreased physical activity levels overall, and widened socioeconomic differences. Yet, preliminary research suggests that consistently meeting physical activity guidelines is associated with a reduced risk of severe COVID-19 outcomes. The pandemic provides a powerful catalyst to advocate for physical activity. Active transportation has been promoted, such as the creation of cycle lanes, open streets, and improved pedestrian infrastructure. Climate and public health communities have been calling for changes to urban design for years. The pandemic showed that when the need is urgent enough and there is political will, action is quick. The challenge now is to maintain and accelerate such changes.

Exercise during lockdowns was considered an essential activity by many governments worldwide—physical activity was seen to be as essential as food, shelter, and seeking medical care. Early government campaigns during COVID-19 encouraged the public to go out and exercise. Why then can governments not commit to promoting physical activity as an essential human need beyond and independent of COVID-19?

The much heightened public awareness about health, presents an opportunity to focus on the benefits of being healthy rather than managing disease. One goal should be to integrate physical activity into the way people lead their lives every day such that the physically active choices, which are often the healthier and more environmentally friendly ones, become the default. Using public transport, active travel, mandatory physical education in schools, and after-school activities are a few possibilities. The pandemic showed how easy it is to go for a 30 min daily walk. By advocating levels of physical activity that people can reasonably integrate into their lives, such as walking, expectations can be managed. Set the bar too high, and people will do nothing. But with reasonable targets, they might just get moving. ■ *The Lancet*



Erin Bakson/Getty Images

Published Online
July 21, 2021
[https://doi.org/10.1016/S0140-6736\(21\)01652-4](https://doi.org/10.1016/S0140-6736(21)01652-4)
See [Comment](#) pages 370 and 373
See [Perspectives](#) page 381
See [Series](#) pages 429, 443, and 456

For more on the [safety of the Olympics](#) see [Editorial Lancet 2021; 397: 2225](#)

For more on the [Physical Activity 2021 Series](#) see www.thelancet.com/series/physical-activity-2021

For the [Physical Activity 2012 Series](#) see <https://www.thelancet.com/series/physical-activity>

For the [Physical Activity 2016 Series](#) see <https://www.thelancet.com/series/physical-activity-2016>

For [worldwide trends in physical activity](#) see [Articles Lancet Glob Health 2018; 6: e1077–86](#)

For the [WHO Global Action Plan on physical activity](#) see <https://www.who.int/publications/i/item/9789241514187>

For [WHO guidelines on physical activity and sedentary behaviour](#) see <https://apps.who.int/iris/bitstream/handle/10665/336656/9789240015128-eng.pdf?sequence=1&isAllowed=y>

For more on [downgrading physical activity in the Global Burden of Disease study](#) see [BMJ 2021; published online April 29. http://dx.doi.org/10.1136/bjsports-2021-104064](#)

For more on [physical inactivity and COVID-19](#) see [BMJ 2021; published online April 13. http://dx.doi.org/10.1136/bjsports-2021-104080](#)