Newsletter of the IASSIDD Health Special Interest Research Group

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The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group (SIRG)'s Mission is to promote physical health of people with IDD. This is done by formulating priorities for health care, research and training and by sharing ideas and results. The SIRG organizes annual roundtables in varying countries around specific themes (see www.iassidd.org).

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AN UPDATE ON PHYSICAL ACTIVITY, EXERCISE AND FITNESS

Introduction

This Newsletter aimed to provide an overview of all the research on Physical Activity, Exercise and Fitness in Individuals with Intellectual Disabilities published between January 2019 and July 2020. We hope this Newsletter showcases the breadth of topics and the quality of the research being performed, and that this will inspire and excite current and new researchers in this field, as well as providing a resource for families, clinicians and other professionals who support individuals with intellectual disabilities (ID).

Our initial Pubmed search resulted in no less than 118 peer-reviewed publications. The main topics were:
-Epidemiology (18 publications),
-Effects of exercise on health and participation (22 publications),
-Effects of behavioral and environmental interventions on lifestyle (18 publications),
-Focus on specific genetic syndromes (32 publications),
-Assessment (15 publications),
-Exercise physiology (2 publications),
-Remote interventions and technology (3 publications), and
-Other (8 publications).

The publications we chose to highlight in the summaries per topic were papers reviewing the current state of the art in systematic reviews or meta-analyses, papers that included larger study samples, papers from underrepresented regions in the world, and papers that introduced a new intervention or took an innovative approach. This decision was driven more by our desire to provide the best possible overview than by a quality assessment per se, meaning that papers not mentioned are by no means of lower quality than the ones we did include.
We also recognize that the COVID-19 pandemic has drastically impacted our research field, and even more so, the lives and activities of individuals with ID and their families around the world. Programs were canceled, in-person activities were reduced, and interaction with others may have been limited over the past 10 months. With thanks to the Wiltshire Council who organized a seminar for physical activity professionals working with individuals with IDD last July (https://youtu.be/xeFF8ZCFOhk), we are also including a number of practical tips on how to stay active during the pandemic that were shared during this webinar.

Thessa and Alyt

Recent Publications

Epidemiology of physical activity, exercise and fitness

More and methodologically stronger studies keep confirming that physical inactivity remains an important concern for health in individuals with ID. Individuals with ID of all ages demonstrate inactive lifestyles and consequently poor physical fitness levels, resulting in negative health outcomes.

A recent large national study in the United States (n = 50,191) showed that children with Down syndrome were significantly less likely to engage in regular physical activity than typically developing children. They were also more likely to watch TV for more than 2 hours/day [1]. Sex differences in physical activity behavior were revealed in a recent systematic review, including 26 papers. Women with ID appeared to be less active than men with ID. The results for sex differences in sedentary behavior were inconclusive [2].

These inactive lifestyles can have negative health consequences, and recent studies are providing new insights. A recent study regarding hypertension found that 48% of adults participating in the Special Olympics were hypertensive [3]. Another study showed that low physical fitness levels are associated with a higher mortality risk, and that being fit was a more important factor than obesity [4]. Older adults with ID who were unfit were almost 4 times more likely to die than people who were fit, regardless of obesity [4]. Moreover, being active (≥ 150 min/week of light to moderate physical activity, or ≥ 75 min/week of vigorous intensity) can reduce mortality risk with 70% in adults with ID [5]. Finally, a novel hypothesis has been proposed (figure 1), and supported with data, that even small differences at the lower end of the physical fitness spectrum are associated with health benefits [6]. These studies support that getting individuals with ID more active would be of great benefits for their health.

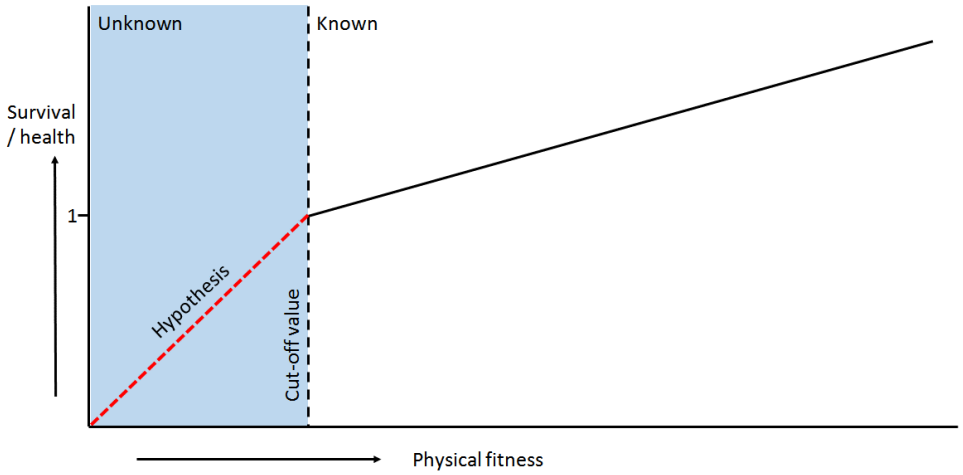


Figure 1. Novel hypothesis of large benefits with small changes in physical fitness at the low end of the fitness spectrum.

Effects of exercise on health outcomes and participation

The body of evidence for the effects of exercise on the health of individuals with ID has increased over the last couple of years. A number of systematic reviews and meta-analysis have recently been performed, showing the positive effects of exercise on health in this population.

Improvements in physical health (e.g. cardiorespiratory fitness, muscle strength, balance, flexibility, reaction time) as well as psychosocial health (e.g. self-efficacy, anxiety and mood) are seen [7-10]. Most studies looked at the effect of exercise on physical health and fewer on psychosocial health. Unfortunately, high risk of bias, small sample sizes, and a lack of good quality measurements impact the strength of the current evidence. Additionally, too little information is available to draw conclusions about the most optimal intervention type, frequency, timing and length. This is an important area for future research to focus on.

It is suggested that sport-related interventions over general physical activity may have the largest impact on

psychosocial outcomes and increase motivation to exercise. However, limited research is available regarding sport-related interventions [7, 10], with only a few recent studies that looked into the effects of such interventions. An 8-week surfing intervention was effective in improving physical fitness in children with developmental disabilities [11]. A 12-week Kin-Ball intervention improved physical fitness in youth and adults with ID [12], and a 6-month soccer program significantly improved soccer skills and physical fitness of adults with ID [13]. Finally, a daily afterschool program in the park lasting 1 to 2 years, consisting of 60 minutes of physical activity sessions combining multiple sports (soccer, kickball, flag football) together with 1-2 times per week nutrition education lessons, improved body composition, blood pressure and cardiorespiratory fitness in children, adolescents and young adults with ID [14].

Effects of behavioral and environmental approaches to achieve an active lifestyle

Besides individual factors, interpersonal and environmental factors are crucial to support a healthy lifestyle. A Dutch research group, together with international colleagues, developed a conceptual framework for healthy settings for individuals with ID, based on the concept mapping method. Factors that were identified specifically for healthy settings for individuals with ID were an universal design of the physical environment, the role of care professionals in the social environment to empower people with ID, possibilities for care providers to contribute to a health-promoting setting, and preconditions that allow people to engage in society [15]. Additionally, assets in the environment for physical activity and healthy nutrition were identified together with individuals with ID and their carers. A total of 185 assets were identified, that could be grouped into 'social network and ways people can support', 'assets in/around places, and person-environment fit', and 'preconditions: health care, prevention, budget and policy' [16]. An asset mapping tool has been developed to create an overview of promoting and protective factors for health in the environment [17]. This tool can aid in creating environments that support healthy lifestyles of individuals with ID.

One of the important factors for being physically active is the support that individuals with ID get to become active. The role of direct support professionals herein is crucial, and a recent study studied which characteristics of the professionals are important for their capability, opportunity and motivation to provide physical activity support to individuals with ID. They identified the characteristics higher age, having received additional training in physical activity support, working in an activity center compared to working in a living unit, and the presence of physical activity plans for individuals with ID [18].

A study focusing on multiple aspects of perceived health and wellbeing, defined as wellness, of Special Olympic athletes and their caregivers and coaches revealed that athletes perceive their own wellness in unique ways compared to their caregivers and coaches [19]. This implies that it is important to tailor health promotion interventions to the perspectives and priorities of individuals with ID. An interesting approach with regard to this is a recent study investigating the peer-to-peer HealthMessages Program. Individuals with ID were trained as health coaches (Peer health coaches) and together with mentors they conducted the 12-week HealthMessages Program with up to ten peers with ID. The peer health coaches improved their knowledge about a healthy lifestyle, mentors improved their self-efficacy, and peer participants improved their knowledge about a healthy lifestyle, social supports, and health behaviors [20]. In another study, a mentor-based school intervention for adolescents with ID was assessed. Within this intervention college students mentored adolescents with ID with regard to healthy food and participating in in a weekly physical activity session of 60-70 minutes for 14 weeks. This mentoring program was found to be feasible and showed preliminary efficacy showed improvements in nutrition and more time spent in physical activity [21].

Physical activity, exercise and fitness in people with specific syndromes

Specific genetic syndromes such as Down syndrome or Rett syndrome can have a distinctly different impact on the needs and capabilities to stay fit and healthy through physical activity and exercise. New studies highlight the need for a focus on physical activity promotion in individuals with Down syndrome, by demonstrating low physical activity levels in specific age-groups, such as middle-aged adults [22] or adults living in different settings [23]. Strides are being made in the body of knowledge supporting the effects of exercise. Three systematic reviews have summarized the evidence regarding health benefits of physical activity for individuals with Down syndrome. The

first review included 19 papers between 2007-2019 and focused solely on physical activity interventions specifically in Down syndrome [24]. They concluded that exercise 'seems to have a positive impact on cardiometabolic risk profile, muscle strength and aerobic work capacity' but that more vigorous experimental designs are required to elucidate the effects of exercise on aerobic capacity, strength, proprioception and cardiometabolic risk profile [24]. This is in line with a second systematic review focusing on the effects of exercise on balance in children with Down syndrome [25]. They found that exercise was indeed successful in improving static balance in children and global balance in adolescents, but evidence was lacking to support exercise as an effective intervention to improve dynamic balance in children and static balance in adolescents [25]. The third review focused on the effects of exercise on body composition in overweight and obese adults with Down syndrome, including English and Spanish publications [26]. They concluded that more and rigorous studies were needed to draw conclusions about the effects of exercise [26]. Innovative types of exercise, such as adapted dancing, could be an effective mode of exercise for individuals with Down syndrome. A small study provided support for the beneficial effects of adapted dance on motor skills and participation in children with Down syndrome [27]. For individuals with Down syndrome, a specific consideration when exercising is atlanto-axial instability, defined as increased movement between the first (atlas) and second (axial) cervical vertebra joint articulation. A new statement from the Faculty of Sport and Exercise Medicine (FSEM) in the United Kingdom summarizes the evidence regarding prevalence and consequences of asymptomatic atlanto-axial instability in individuals with Down syndrome, and published a statement on preparticipation screening for this population to promote safe physical activity and sport for all [28].
Although Down syndrome is the most prevalent genetic syndrome as a cause of ID, other genetic syndromes are the focus of physical activity research as well. Facilitators and barriers of activities were investigated in girls and women with Rett syndrome, and through thematic analysis, one central theme emerged: a constant balance to do the best thing for the girl or woman [29]. Within the central theme, five subthemes of facilitators and barriers were identified relating to the individual and the physical, organizational, social, and attitudinal environments [29]. These findings support a multifactorial approach to physical activity promotion, with intervention targets at different environmental levels to promote change.

Assessment of physical activity, exercise and fitness

New knowledge keeps developing with regards to the assessment of physical activity behaviors and fitness. The current research underlines the need to critically evaluate cut-points and prediction models that were designed with a different population in mind, and to investigate necessary adaptations to individuals with ID. A systematic review of studies using accelerometry to determine cut-off points for different pediatric clinical populations (including ID) identified various cut-off points [30]. They found a range of disease-specific MVPA cut-points from 152 to 735 counts/15 s, with lower cut-points found for inherited muscle disease and higher cut-points associated with ID. The authors recognized that the cut-points were lower for populations with both ambulatory and metabolic impairments, likely reflecting the higher energetic demands associated with those conditions [30]. A recent study comparing adults with Down syndrome with controls found that higher energy expenditure during walking is strongly related to higher step rate squared and lower BMI, and not having Down syndrome, which is contradicting some of the previous studies [31]. This is relevant as other research found that individuals with Down syndrome took shorter and wider steps, and are experiencing more variability of most spatiotemporal parameters [32]. Individuals with ID, and individuals with Down syndrome in particular, are always strategizing between optimizing efficiency and safety, and it is important to include these considerations in the discussions about adhering to public health guidelines and assessment methods.

With regards to fitness, most of the recent research is focusing on psychometric properties of new, adapted and existing instruments. Measuring physical fitness is challenging in individuals with ID, and more (adapted versions of)

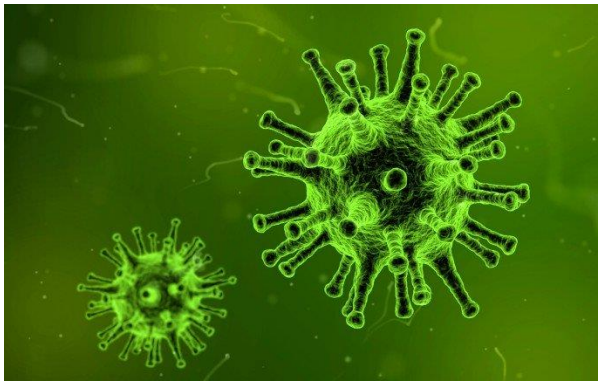
tests exists of which we do not know the psychometric properties. This makes it hard for researchers and clinical professionals to select a suitable test for their specific purpose. In an effort to provide a good alternative, a recent study developed a new strength index combining four separate tests (timed stand test, partial sit-up test, seated pushup and handgrip test) into one index, thus better grasping the different aspects of strength in individuals with ID [33]. A recent overview article described a selection of tests that currently satisfy the criteria for feasibility, reliability, and validity, and of which reference data is available to allow for interpretation of individual outcomes [34]. The ID-fitscan, as the authors called this selection of tests, includes tests for body composition (BMI, waist circumference), muscular strength (grip strength), muscular endurance (30 second and five times chair stand), and balance (static balance stances, comfortable gait speed) [34]. However, more research is necessary into psychometric properties of other tests to be able to recommend them as well. Additionally, combining physical fitness data on this population in larger datasets would be necessary to arrive at reference values for individuals with ID.

Remote interventions and technology

A recent paper presents an overview of technology-aided support tools to promote any kind of activities in individuals with ID, including those with more severe physical or cognitive limitations [35]. They make a distinction between tools to promote adaptive responses, to promote functional tasks, and to promote communication, leisure or both. Tools vary from providing a positive response like music when the participant takes a step in a walker, to showing a virtual interactive coach on an LCD touchscreen to support an assembly task, and from providing timed cues as a reminder for daily tasks to tools to independently start video calls or games on an IPad [35].

COVID-19, and how to stay active during a pandemic

In the past 10 months of the COVID-19 pandemic, the switch to online delivery of many services and activities has resulted in positive and negative outcomes. Positive outcomes have been increased skills to communicate through various platforms (Zoom, Teams, Facebook etc.), with more independence and easier access to (more online) activities across the country and the world (see this article in the Guardian https://www.theguardian.com/world/2020/apr/20/covid-lockdown-opening-up-world-for-people-with-disabilities).
Negative outcomes are the risk of isolation and loss of activities without a good alternative.
To support alternatives in these trying times, we would like to provide some ideas on how to stay physically active during the pandemic. These ideas were generated by the audience of health care professionals during a webinar last July on 'Physical activity and fitness for people with learning disabilities' (hosted by Wiltshire Health and Care, UK with Wiltshire Council and the Association of Chartered Physiotherapists for People with LD, South West England and Wales).



Ideas on how to stay active during the pandemic:

- Participate in virtual exercise sessions of Zumba, yoga, Tai Chi, dance classes, circuit training, 'Have A Go At Home' etc. Look for sessions that are adapted to individuals with ID or Down syndrome, or targeted to other audiences that are at a lower fitness level.
- Make an obstacle course inside or outside the house.
- Garden bowls, balloon keepy-uppy, chair yoga.
- Taking part in general household activities while putting more emphasis on participation that outcome.
- Treadmill or stationary bike in the house while watching your favorite show.
- Organizing a Route 66 or Tour de France for residents on static and adapted bikes, for example led by one of the residents. More motivating and giving purpose instead of just getting on the bike for 20 minutes.
- Games / charades / circuit training over Zoom with friends / group members of a previous in-person activity.

- Quizzes etc where solving the clues requires an element of physical activity, but the participant has the focus on solving the clues and not the exercise piece. It helps to encourage participation that can be built on.
- Online theater or singing classes, or even preparing an online show with the same group someone was part of for in-person classes.
- Walking with some circuit training exercises in the middle.
- Dancing, circuit training in the garden, bouncing on peanut ball, long walks, walking with heavy back pack (carrying drinks in bag), ball games, use of fitness videos, gardening, heavy domestic activities- carrying such as laundry up and downstairs, carrying shopping, family disco, bubble bursting, balloon games.
- Inclusive cycling in safe off-road environments - cycling with friends / family / households / 'bubbles'.
- Make regular Zoom sessions / walks part of the new routine.

References

References

1. Diaz, K.M., *Physical Activity and Sedentary Behavior Among U.S. Children With and Without Down Syndrome: The National Survey of Children's Health.* Am J Intellect Dev Disabil, 2020. **125**(3): p. 230-242.
2. Westrop, S.C., et al., *Gender differences in physical activity and sedentary behaviour in adults with intellectual disabilities: A systematic review and meta-analysis.* J Appl Res Intellect Disabil, 2019. **32**(6): p. 1359-1374.
3. Schroeder, E.C., et al., *Hypertension in Adults With Intellectual Disability: Prevalence and Risk Factors.* Am J Prev Med, 2020. **58**(5): p. 630-637.
4. Oppewal, A. and T.I.M. Hilgenkamp, *Is fatness or fitness key for survival in older adults with intellectual disabilities?* J Appl Res Intellect Disabil, 2020. **33**(5): p. 1016-1025.
5. Diaz, K.M., *Leisure-time physical activity and all-cause mortality among adults with intellectual disability: the National Health Interview Survey.* J Intellect Disabil Res, 2020. **64**(2): p. 180-184.
6. Oppewal, A., D. Maes-Festen, and T.I.M. Hilgenkamp, *Small Steps in Fitness, Major Leaps in Health for Adults With Intellectual Disabilities.* Exerc Sport Sci Rev, 2020. **48**(2): p. 92-97.
7. Bondár, R.Z., et al., *The effects of physical activity or sport-based interventions on psychological factors in adults with intellectual disabilities: a systematic review.* J Intellect Disabil Res, 2020. **64**(2): p. 69-92.
8. Bouzas, S., R.I. Martinez-Lemos, and C. Ayan, *Effects of exercise on the physical fitness level of adults with intellectual disability: a systematic review.* Disabil Rehabil, 2019. **41**(26): p. 3118-3140.
9. Kapsal, N.J., et al., *Effects of Physical Activity on the Physical and Psychosocial Health of Youth With Intellectual Disabilities: A Systematic Review and Meta-Analysis.* J Phys Act Health, 2019. **16**(12): p. 1187-1195.
10. St John, L., G. Borschneck, and J. Cairney, *A Systematic Review and Meta-Analysis Examining the Effect of Exercise on Individuals With Intellectual Disability.* Am J Intellect Dev Disabil, 2020. **125**(4): p. 274-286.
11. Clapham, E.D., et al., *Effectiveness of surf therapy for children with disabilities.* Disabil Health J, 2020. **13**(1): p. 100828.
12. Zurita-Ortega, F., et al., *Effects of an Alternative Sports Program Using Kin-Ball in Individuals with Intellectual Disabilities.* Int J Environ Res Public Health, 2020. **17**(15).
13. Barak, S., et al., *The Game of Life soccer program: Effect on skills, physical fitness and mobility in persons with intellectual disability and autism spectrum disorder.* J Appl Res Intellect Disabil, 2019. **32**(6): p. 1401-1411.
14. Messiah, S.E., et al., *Changes in cardiovascular health and physical fitness in ethnic youth with intellectual disabilities participating in a park-based afterschool programme for two years.* J Appl Res Intellect Disabil, 2019. **32**(6): p. 1478-1489.
15. Vlot-van Anrooij, K., et al., *Towards healthy settings for people with intellectual disabilities.* Health Promot Int, 2020. **35**(4): p. 661-670.
16. Vlot-van Anrooij, K., et al., *How can care settings for people with intellectual disabilities embed health promotion?* J Appl Res Intellect Disabil, 2020. **33**(6): p. 1489-1499.
17. Vlot-van Anrooij, K., et al., *Improving Environmental Capacities for Health Promotion in Support Settings for People with Intellectual Disabilities: Inclusive Design of the DIHASID Tool.* Int J Environ Res Public Health, 2020. **17**(3).
18. Bossink, L.W.M., et al., *Factors associated with direct support professionals' behaviour in the physical activity support provided to people with intellectual disabilities.* J Intellect Disabil Res, 2019. **63**(8): p. 981-991.
19. Hamdani, Y., et al., *Multi-stakeholder perspectives on perceived wellness of Special Olympics athletes.* Disabil Health J, 2019. **12**(3): p. 422-430.
20. Marks, B., et al., *Effectiveness of a HealthMessages Peer-to-Peer Program for People With Intellectual and Developmental Disabilities.* Intellect Dev Disabil, 2019. **57**(3): p. 242-258.

21. An, J., et al., *A school-based mentoring program developing healthy behaviors of adolescents with intellectual and developmental disabilities: A pilot feasibility study.* Disabil Health J, 2019. **12**(4): p. 727-731.
22. Mihaila, I., et al., *Leisure activity in middle-aged adults with Down syndrome: Initiators, social partners, settings and barriers.* J Appl Res Intellect Disabil, 2020.
23. Oreskovic, N.M., et al., *Physical activity patterns in adults with Down Syndrome.* J Appl Res Intellect Disabil, 2020.
24. Paul, Y., et al., *The health benefits of exercise therapy for patients with Down syndrome: A systematic review.* Afr J Disabil, 2019. **8**: p. 576.
25. Maiano, C., et al., *Do Exercise Interventions Improve Balance for Children and Adolescents With Down Syndrome? A Systematic Review.* Phys Ther, 2019. **99**(5): p. 507-518.
26. Martinez-Espinosa, R.M., M.D. Molina Vila, and M. Reig Garcia-Galbis, *Evidences from Clinical Trials in Down Syndrome: Diet, Exercise and Body Composition.* Int J Environ Res Public Health, 2020. **17**(12).
27. McGuire, M., et al., *Adapted Dance Improves Motor Abilities and Participation in Children With Down Syndrome: A Pilot Study.* Pediatr Phys Ther, 2019. **31**(1): p. 76-82.
28. Tomlinson, C., et al., *Sport Preparticipation Screening for Asymptomatic Atlantoaxial Instability in Patients With Down Syndrome.* Clin J Sport Med, 2020. **30**(4): p. 293-295.
29. Stahlhut, M., et al., *Facilitators and Barriers of Participation in "Uptime" Activities in Girls and Women With Rett Syndrome: Perspectives From Parents and Professionals.* Qual Health Res, 2019. **29**(4): p. 609-619.
30. Bianchim, M.S., et al., *Calibration and validation of accelerometry using cut-points to assess physical activity in paediatric clinical groups: A systematic review.* Prev Med Rep, 2020. **19**: p. 101142.
31. Bertapelli, F., et al., *Predicting the rate of oxygen uptake from step counts using ActiGraph waist-worn accelerometers in adults with Down syndrome.* J Intellect Disabil Res, 2020. **64**(8): p. 602-611.
32. Beerse, M., et al., *Variability of spatiotemporal gait parameters in children with and without Down syndrome during treadmill walking.* Gait Posture, 2019. **68**: p. 207-212.
33. Merchan-Baeza, J.A., et al., *Development of a new index of strength in adults with intellectual and developmental disabilities.* Disabil Rehabil, 2020. **42**(13): p. 1918-1922.
34. Oppewal, A. and T.I.M. Hilgenkamp, *Adding meaning to physical fitness test results in individuals with intellectual disabilities.* Disabil Rehabil, 2019: p. 1-8.
35. Lancioni, G.E., et al., *Recent Technology-Aided Programs to Support Adaptive Responses, Functional Activities, and Leisure and Communication in People With Significant Disabilities.* Front Neurol, 2019. **10**: p. 643.