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Successful Online Exercise Intervention Studies for Individuals With Intellectual Disabilities Including Down Syndrome: Best Practices and Recommendations

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ABSTRACT

Background: Online exercise interventions can improve access to tailored programmes for individuals with intellectual disabilities (including Down syndrome). This paper aimed to describe best practices and provide recommendations for online physical activity or exercise programmes for this population.

Method: Two research teams with extensive experience delivering online physical activity and exercise interventions in > 240 individuals with intellectual disabilities, combined with input from participant/caregiver dyads, describe adaptations to online delivery of programmes with regard to development, recruitment, data collection, intervention delivery, communication and staff requirements, based on two specific online programmes.

Results: Adaptations to an online delivery are necessary for every aspect of exercise interventions for individuals with intellectual disabilities. All phases benefit from input from the community.

Conclusion: When the appropriate adaptations are made for online delivery, as described in this paper, online physical activity or exercise interventions can be highly successful for individuals with intellectual disabilities.

1 | Introduction

Individuals with intellectual disabilities experience disproportionately high rates of obesity and related chronic conditions which impact their health and quality of life (Hsieh et al. 2014). This includes individuals with Down syndrome, who experience Down syndrome-specific comorbidities that have been extensively reviewed elsewhere (Capone et al. 2018; Capone et al. 2020). Physical activity participation may help counter these conditions by providing health benefits such as weight loss and maintenance, muscle strength, bone health, physical function for daily activities and reduced risk of chronic diseases including mental health problems like depression (Warburton et al. 2006). There are no physical activity guidelines specifically for this population, even though some population-specific characteristics may affect absolute and relative intensity of physical activities (ACSM 2022a). The American Academy of Paediatrics does not provide any specific guidance for individuals with Down syndrome with regard to physical activity guidelines. It is therefore recommended to use the physical activity guidelines for the general population (DHHS 2022; WHO 2020), realising that activities might be more intense for individuals with intellectual disabilities and/or Down syndrome. Adolescents and adults with intellectual disabilities, including

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Summary

- Online physical activity or exercise interventions can be very successful for individuals with intellectual disabilities, including Down syndrome.
- To make online programmes successful, specific adaptations to the programme and its delivery are necessary.
- Individuals with intellectual disabilities, including Down syndrome, enjoyed participation in the online exercise programme and felt connected and successful.
- Online exercise interventions improve access to tailored exercise programmes and to specialised, trained instructors.

individuals with Down syndrome, have low rates of physical activity participation (Diaz 2020; Esposito et al. 2012; Helsel et al. 2024; Hilgenkamp et al. 2012; Oreskovic et al. 2020) with evidence that fewer than 10% of adults with intellectual disabilities meet the recommended physical activity guidelines (Dairo et al. 2016). Hindrances to physical activity performance in this population include unique factors such as lack of transportation to exercise facilities, few supportive peers, lack of parental/staff involvement, inadequate facilities, few opportunities at day programmes and few exercise staff trained to work with this population (Bodde and Seo 2009; Jacinto et al. 2021; Mahy et al. 2010; Michalsen et al. 2024). Interventions which consider these factors are needed.

A promising strategy for increasing physical activity and fitness in this population is the remote delivery of live exercise classes adapted to the needs of people with intellectual disabilities, including Down syndrome, from here on referred to as individuals with intellectual disabilities. Remote delivery (via live video conferencing) eliminates the need for transportation and utilises disability-informed instructors addresses the problem of lack of adapted physical activity instructors in community gyms and fitness centres. The live component provides real-time social interaction, as the instructor and participants can see and hear one another and make modifications to movements if needed. Interaction with peers can be incorporated into the class to build a supportive environment for the participants. Initial interventions providing a remotely delivered live exercise programme to adults with intellectual disabilities have shown the potential to improve balance, strength, walking patterns and speed, and elicit weight loss in this population (Guerrero et al. 2023; Hilgenkamp et al. 2024; Ptomey et al. 2015). Another online study demonstrated improved physical and cognitive health, and psychosocial outcomes (Merzbach et al. 2023; Merzbach et al. 2024). The online delivery of exercise interventions requires additional adaptations with regards to recruitment and data collection. The objective of this paper is to use an inclusive approach to describe best practices for conducting studies on remote physical activity interventions with adults with intellectual disabilities including Down syndrome from two academic research centres that have spent over a decade developing strategies for remote delivery of exercise and successfully deployed these interventions to over $n = 240$ people with intellectual disabilities in both clinical trials and community programmes. These two teams of clinicians and researchers have extensive experience working with adults with intellectual disabilities, including with individuals with Down syndrome specifically, and include five PhDs with expertise in physical activity, two physical therapists, one occupational therapist, and one clinical exercise physiologist, all with at least 10 years of experience working with individuals with intellectual disabilities. Detailed descriptions of the development and assessment of these exercise programmes may be found in our previously published reports (Guerrero et al. 2023; Helsel et al. 2023; Hilgenkamp et al. 2024; Mann et al. 2023; Ptomey et al. 2017; Ptomey et al. 2020; Ptomey, Barton, et al. 2024; Ptomey, Szabo, Willis, Gorczyca, et al. 2018; Ptomey, Washburn, et al. 2024; Suire et al. 2025); however, this paper will be centred around two specific online programmes (Mann et al. 2023; Ptomey et al. 2020). Consensus discussions with both research groups took place to arrive at these recommendations, and other literature was consulted for specific aspects of recruitment, participant involvement, familiarisation, etc. This literature is provided throughout this paper as suggested reading materials for additional detail. Experiences of participants with intellectual disabilities and their families were included as well, based on survey and interview data about their experiences participating in these two specific programmes (Bodde et al. 2024; Hilgenkamp and Mann 2024). The studies using these programmes followed the US Federal Policy for the Protection of Human Subjects, were evaluated by the Institutional Review Board and all participant/caregiver dyads have provided written informed consent prior to inclusion in the studies (NCT04048759 and NCT04854122). Based on the experiences with these two specific programmes of both the research teams as well as adults with intellectual disabilities and their families, this paper will provide recommendations for the development of online programmes, as well as for recruitment and data collection, execution of the intervention, staff training and how to incorporate participant feedback.

2 | Best Practices for Development of the Programme

2.1 | Strategies for Developing an Exercise Intervention

The actual content of the exercise interventions is dependent on the choice of setting, target audience and goals of the intervention, as well as resources available for execution of the intervention. We refer to the ACSM Guidelines for Exercise Testing and Prescription (ACSM 2022b) for recommendations on frequency, intensity, duration and type of exercise interventions, but recognise the need for more detailed guidance when developing new, theory-based exercise programmes (O'Cathain et al. 2019), such as Intervention Mapping (Bartholomew et al. 1998). When adapting an existing programme to a new setting or audience, specific strategies to do this in a systematic way can be found through FRAME (Wiltsey Stirman et al. 2019) or by using the ADAPT guidance (Moore et al. 2021). Acknowledging that content will need to be different for or adapted to each unique situation, we have provided descriptions of exercise interventions as designed by the authors in Table 1. It is important to consider that the

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TABLE 1 | Details of discussed online exercise programmes.

	Mann Method PT Exercise Program	MOVE-DS Program
Target audience	Adults with Down syndrome	Individuals with Down syndrome and other intellectual and developmental disabilities
Content	The Mann Method Physical Therapy (PT)-Based Exercise Program is a 12-week, 3×/week, 1 h/session, online physical therapy-based multicomponent exercise programme for adults with Down syndrome (Mann et al. 2023), with exercise progressions every third session of the week. This programme is based on specific physical needs of individuals with Down syndrome as reviewed with the ICF Framework, and addresses these with regards to endurance, balance, strength and flexibility. The five components of this programme are Cardiovascular Endurance, Foundational Exercises, Hip Strengthening Exercises, Visual-Vestibular Exercises and Stretches. The consistent order of the age-appropriate exercises facilitates building a routine. The consistent cueing and use of a visual chart supports routine and adherence, as well as independence and creating successful experiences. The consistency of exercise time and exercise instructor are recommended.	The MOVE-DS sessions include a warm-up (~5 min) followed by moderate-to-vigorous intensity aerobic and resistance exercise (~35 min) and cool-down/stretching (~5 min). Exercises are accompanied by music and include walking/jogging, dancing, imitating animal movements, vertical/horizontal jumps, high knees and squats. For each exercise the instructor should provide a modification for individuals who may have a hard time or are unable to perform specific movements. Exercise sessions should aim to target all major muscle groups. A variety of 'themes' can be used for classes which engage the imagination and promote participation. Class themes may rotate on a weekly basis and are developed to encourage autonomy and social participation through progressive skill building. For example, the first half of a basketball skills class focuses on strength and agility drills such as jumping, shuffling side to side, dribbling, shooting, etc. In the second half, participants build upon these skills and use them in a gamified approach where they are instructed to dribble an imaginary ball/scarf and pass it to someone else on the screen. The instructor may then split the group into teams with half of the class blocking shots by jumping in place whilst the other half dribbles and shoots. The class may end with the instructor letting participants choose which exercises they would like to practice by giving participants the opportunity to lead the group through the exercise. Examples of themes may include: turbo speed, dance, move like an animal, hiking up a mountain, etc.
Materials required	Wall decal stickers for visual cues Fitball and base (55 cm or 65 cm depending on participant height) ½″ thick exercise mat Large sensory ball Small sensory ball 5 lbs dumbbell 3 lbs dumbbell Exercise step Resistance bands	Resistance bands Throwing scarves Miniature cones Heart rate monitor (Smartwatch) Exercise mat (preferred but not required)
Education	Two education sessions in total, one education session for families 3–4 weeks after the start of the programme, addressing individual progress and rationale for exercises based on Down syndrome-specific physical characteristics, and one education session at the end to discuss individual improvements and follow-up strategies.	Twice monthly individual 20-min education/support sessions are delivered to all participants and a caregiver to educate and support participants with increased daily PA. Each session includes a review of self-monitoring data from the smart watch, goal setting, strategies to increase PA and discussion of a topic relevant to PA.

(Continues)

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TABLE 1 | (Continued)

	Mann Method PT Exercise Program	MOVE-DS Program
Instructor requirements	They may have an exercise certification through a reputable organisation like the ACSM, NASM or NSCA. Instructors delivering the Mann Method program must undergo a training programme developed and overseen by a physical therapist. They must be able to easily navigate the technological requirements of an online programme. They must also be amenable and committed to the delivery of the exercise programme as it is written with the established coaching framework.	All exercise instructors hold at least a baccalaureate degree in exercise science, special education or related field. New instructors undergo a training programme developed and overseen by an occupational therapist.

demonstrated effectiveness of a programme may not translate to a different setting and can be affected by adaptations made, and it is strongly recommended to investigate the effectiveness of a programme in a new setting or adapted version.

2.2 | Adapted to Target Population's Specific Characteristics With Regards to Exercise

Exercise interventions need to be tailored to their specific audience. This is also true for online exercise interventions for individuals with intellectual disabilities. The complexity of activities and instructions should match the level of intellectual disability and motor development levels of the target audience, not just for children and teens with intellectual disabilities who are still in their developmental phase, but for individuals with intellectual disabilities of any age, including older adults. Specific physical limitations can be more prevalent and need to be considered in the choice of exercises, such as spasticity, mobility limitations or concerns about balance and fall risk. For individuals with genetic syndromes that may include condition-specific physical, intellectual or emotional-behavioural features, it may be helpful to do a systems review following the ICF Framework, as done for individuals with Down syndrome (Mann et al. 2023). For safe participation in exercise testing and programming, it is recommended to follow the specific chapter in the ACSM's guidelines for exercise testing and prescription for individuals with intellectual disabilities and with Down syndrome (ACSM 2022a). This includes physician clearance for exercise and possibly a physical evaluation, especially for concerns related to joint instability and cardiovascular concerns (ACSM 2022a).

The level of support available at home needs to be assessed and considered in designing the intervention. For example, support from a family member may be needed throughout to motivate some participants, or not needed at all for others, even being demotivating for some (Ptomey, Washburn, et al. 2024). For example, post-study interviews with caregivers at one site demonstrated that many young adults with Down syndrome did not want caregiver involvement, with one caregiver stating, 'If we did it together, I would love it but she would hate it. Haha! She doesn't even want me in the same room when she is doing the Zoom classes. She likes to be independent like any other teenager' (Bodde et al. 2024). Assistance with the technical setup tends to be necessary the first few sessions, but the majority of the participants with intellectual disabilities were able to independently set up after that. For some participants, physical assistance from a family member may be helpful for some adaptations or for correct and safe execution of exercises, but after the first few sessions, the need for this generally disappears.

2.3 | Input From Community Advisory Board (CAB)

Active community participation in designing effective physical activity programmes for people with intellectual disabilities ensures specific community needs are met and considers valuable lived experience. Methods to ensure community input and representation include conducting community needs analyses, formulation of a CAB and hiring self-advocates to serve on the research team. Although the size and frequency of the advisory board will depend on your local context and programme development timeline, we have found that boards of four to eight people meeting quarterly are ideal. This small group size allows for all participants to contribute to the discussion, and quarterly meetings balance regular touchpoints with the CAB without excess burden on the participants' time (Newman et al. 2011). Board members can discuss physical activity and other health-associated issues, provide input on study design, session content, recruitment strategies and future research or community programming needs. In addition, online needs analysis surveys can be used to measure community interest and barriers in establishing community physical activity programmes.

3 | Best Practices for Recruitment

3.1 | Recruitment Strategies

Recruitment of any underrepresented population comes with opportunities and challenges. Recruiting for studies involving individuals with intellectual disabilities requires a multi-faceted approach utilising existing outreach opportunities such as electronic newsletters and social media, as well as physical locations, using flyers or personal interaction at community events and/or sports. Strong relationships with community partners and community organisations can facilitate outreach and opportunities

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to inform a wide network of families about opportunities for participation. Family-to-family referral can be an impactful recruitment strategy when families have positive experiences with participating in previous or current research studies. One of the main benefits of an online exercise programme is the accessibility to communities who would not otherwise be able to participate, such as those from different states, rural areas or families with limited mobility options. Depending on the target population of the study, recruitment strategies should aim to specifically reach out to these communities, which includes approved translations of all the recruitment materials if applicable. Recruitment staff should ideally have strong rapport with individuals with intellectual disabilities and their families. This can be built through years of experience, volunteering at community events and being actively involved in the CAB.

For settings where individuals with intellectual disabilities or Down syndrome do not live with their family (anymore), such as older adults or in different countries/health care organisation systems, a strong collaboration with health care provider agencies/organisations is imperative for recruitment and execution. In those collaborations, optimal collaboration and commitment of managers and staff of these care provider agencies are needed for any research study that takes place with their clients. Successful strategies to inform and motivate managers and staff include educational sessions and providing clear and concise written information (Hamers et al. 2017; Hilgenkamp et al. 2011). Additionally, informed consent procedures need to be adapted to be as accessible and inclusive as possible, whilst following the applicable rules and regulations of that particular country, state or setting. For more detail on specific considerations and strategies for adaptations for recruitment and informed consent from an international perspective, we refer to Mulhall et al. (2021).

3.2 | Reasons to Participate

It is important to understand motivation to participate in research studies for individuals with intellectual disabilities. Motivation to participate may include the perceived present and future benefit for individuals with intellectual disabilities, consideration of the lack of research for these populations compared to other populations and the urgency of some of the population-specific health concerns. On a more individual level, reasons for participation can include learning something new about yourself or your body, creating new and positive experiences in a new environment, expanding horizons or meeting new people and providing opportunities to connect and interact with peers with or without intellectual disabilities. Interviews with 20 caregiver/participant dyads at one site revealed that over half of participants enrolled in an online exercise study because they were motivated to get healthier, be more active or lose weight (Bodde et al. 2024). Additionally, 25% stated that they were motivated to participate to make a contribution to Down syndrome research efforts: [wanting to] '....help people in the future, and the more research that we can have on Down syndrome the better' (Bodde et al. 2024). A survey amongst 29 caregiver/participant dyads at another site revealed a similar pattern, with 50% of dyads citing reasons for participation related to starting a workout routine and getting healthier, and almost a third said learning more/increasing knowledge was the reason for participating (Hilgenkamp and Mann 2024). For some studies, participation in free assessments that would otherwise be costly, free exercise equipment or shoes and free participation in a tailored exercise programme can be motivators for participation. For randomised clinical trials, researchers could explore offering the exercise programme to the control group after completing the study as exercise may be their primary motivator for joining a study. For example, structured interviews following clinical exercise trials at one site found that 90% of parents in an adolescent exercise study and 96% of participants with Down syndrome in an adult exercise study were interested in continuing classes if offered after completing the trial (Ptomey et al. 2017; Ptomey, Szabo, Willis, Greene, et al. 2018). At another site where a follow-up class was offered to participants who had completed the study, more than 50% continued to participate in this class (Hilgenkamp and Mann 2024). Interviewees from the studies emphasised that social interaction made participating in the exercise classes more enjoyable (Ptomey et al. 2017; Ptomey, Szabo, Willis, Greene, et al. 2018).

3.3 | Barriers to Participation and Solutions

Due to the lack of research for individuals with intellectual disabilities, communities may have a low exposure to research participation and experience barriers related to unfamiliarity with what research or research participation entails (Baumer et al. 2022; Kyprianou et al. 2023; Lott et al. 2022). It is of the utmost importance to provide detailed information about the study, with complete transparency about what participation would include using pictures or videos of the study procedures. This includes explanations of the role of the institutional review board and/or connecting families with families who have previously participated. It is important that potential participants and their families understand the basic concepts of informed consent and assent of the individual with intellectual disabilities, including the option to not participate in any or all of the study procedures. Allowing the caregiver to be present as much as possible during data collection or study visits can take away some of these concerns as well, and it is important to emphasise that any unfamiliar procedures will be practiced and explained/demonstrated before the actual data collection.

Other strategies successfully used by both academic centres to promote inclusion and access to families during in-person study visits include: offering free parking, reimbursement for transportation costs, easy-to-find and accessible location (providing clear and detailed directions including pictures/maps), bilingual test instructors, consistency of study staff across visits to promote familiarity and as much flexibility for scheduling study visits as possible within the study environment (evenings, weekends, etc.).

4 | Best Practices for Data Collection and Study Visits

Data collection for online exercise interventions can be online or in-person, and both research groups have experience with both environments. As for all research, clear communication about the appointment details for the study visits and pre-visit

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requirements with regard to fasting, caffeine, alcohol consumption and exercise engagement need to be clearly communicated, with a reminder sent out the day before. Additionally, the research team must ensure that the families and participants are well-informed about what to expect for each visit, for example, how long the total visit lasts or when exactly certain outcome assessments will take place, especially the more challenging ones such as blood draw, if applicable. Social stories, such as videos or pictures of the testing location, who the research staff will be and what assessments will be done, are a helpful tool to prepare study participants for the data collection visit (Test et al. 2010). For example, a video detailing specific test materials, what will happen for a specific assessment in detail or showing the route to the testing location can be very helpful. For families and individuals with intellectual disabilities, last-minute changes in family schedules can be common, and flexibility in rescheduling study visits benefits both the participants and the research team. Aiming for a 2–3-week window to complete all assessments can be helpful to create that flexibility. In general, study procedures should follow ACSM's guidelines for exercise testing for individuals with intellectual disabilities and/or with Down syndrome (ACSM 2022b).

4.1 | Data Collection Environment

The following information pertains to either the environment at home when the data collection takes place virtually (e.g., over Zoom or another platform), or when data collection takes place in person at a testing location (lab, hospital, community centre, etc.). In addition to an accessible and easy-to-find location, it is important that the space utilised for data collection is inviting, spacious, clean and well-lit to accommodate visual impairments, which are more prevalent in individuals with intellectual disabilities. Considering the high prevalence of differences in processing and experiencing sensory information in individuals with intellectual disabilities, it is recommended to avoid distracting visual information (no equipment or materials present not needed for data collection), olfactory information (no food or cosmetic smells), auditory information (no distracting sounds such as people talking, or other noise) and a private space to ensure confidentiality (no unfamiliar people walking in and out), as much as possible.

4.2 | Choice of Measurements

In addition to selecting data collection methods or measurements that are aligned with the aims of the study, validity, reliability and feasibility need to be taken into account (Oppewal and Hilgenkamp 2020). Preferred measurements are participant-friendly, non-invasive and either familiar or easy to familiarise with, by demonstrating/modelling or practising (see below). Some examples of valid, reliable and feasible tests for online assessment for individuals with intellectual disabilities are provided by Guerrero et al. (2023) and Hilgenkamp et al. (2024).

4.3 | Familiarisation

Since any research study will incorporate elements that are new to the participant, familiarisation is recommended for all study procedures, but specifically for new and challenging ones. Familiarisation can range from showing the equipment before using it (for easy/familiar tasks like measuring height and weight), to more involved with demonstrating/modelling the task first, engaging the participant in the process (pushing a button to start) and practicing until comfortable with the task/equipment. This process will use some of the communication strategies discussed in Section 6, such as one-step instructions, positive feedback, small steps and visual cues more than verbal instructions. One of the participant/caregiver dyads said about the study visits: 'They explained everything and were so patient during both lab visits. My daughter watched the videos ahead of time so she knew what to expect and she loved all the encouragement and positive feedback while she was there' (Hilgenkamp and Mann 2024).

4.4 | Set Up of Study Visits

When designing the study visits (either online or in-person), some important considerations are recommended for research with individuals with intellectual disabilities. Based on the experiences of the research teams, the total duration of each study visit is recommended not to exceed 2 h of engaged participation to avoid fatigue and decreased motivation to participate. It is also important to include sufficient time and opportunity for bathroom breaks and water breaks. Personal preferences and needs may deviate from this, and the schedule should allow for some flexibility (no back-to-back scheduling). If needed, more than one study visit is a preferred solution over extending study visits beyond 2 h.

The order of study procedures during the study visits should be carefully considered. In addition to task-specific requirements for specific fitness tests (not doing a balance test after a maximal exercise test for example), it is valuable to arrange the procedures from easy/familiar to more challenging, so there is time to build trust and rapport with the participant, and to establish a collaborative relationship. This allows for time to get to know the participant's communication styles and preferences and demonstrates the commitment to listening and respecting the participant's agency. Additionally, the order of study procedures should avoid fatigue and discomfort as much as possible by optimising efficiency of movements and avoiding unnecessary repetitive movements on and off equipment, to and from other rooms, taking shoes off and putting them on, standing up/laying down, as that can be challenging for many participants with intellectual disabilities.

4.5 | Communication During Data Collection

Considering that most participants are unfamiliar with the research environment, communication with participants and their family needs to be transparent, clear, respectful, kind and positive. At the start of the study visit, it is recommended to allow for some time to get comfortable in the new space and/or online setup. Keep communication clear yet simple: avoid unnecessary information, long sentences and complicated words about what is going to happen in the study visit. Engage both the participant and the family member in the conversation and take

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the time to listen to their responses. Active listening and making sure families understand the information is the start of building a relationship based on trust and reliability. With regards to the instructions for the test procedures, it is recommended to use the strategies described in Section 6, including one-step instructions, visual demonstrations, positive language and encouragement throughout, and action-oriented language such as 'Let's move to this chair'. If test procedures consist of multiple steps for preparation or execution, use a consistent order for these steps in both practicing and executing, so the participant feels confident in what will happen next. To allow for the family to continue to feel included, build in check-ins to see if they have any questions.

5 | Best Practices for the Exercise Intervention

5.1 | Intervention Content: Exercise and Education

As described in Section 2, the content of the exercise programme is dependent on many factors, including setting, goals, audience and resources. However, based on the experiences of both research groups and general exercise goals for individuals with intellectual disabilities, some specific remarks can be made. Generally, it is recommended to design a multi-faceted exercise intervention. This means that it includes both strength and endurance exercises, and ideally also balance and flexibility exercises. As many individuals with intellectual disabilities are not meeting the physical activity guidelines, nor the recommendations for strength or balance training, an exercise programme needs to address all these fitness components that go hand in hand to drive improvements in functional activities and independence. For example, without leg strength it is hard to work on endurance, and walking outside is hard if balance concerns are not addressed. Another joint recommendation from both research groups is using music as a key motivator for specific sections of the exercise sessions, specifically for warm-up or cardiovascular endurance sections. As described, using participants' personal favourites or generally upbeat and/or expressive songs can be motivating and allows for personal expression. With regards to the duration of each session, the research groups have had success with sessions between 40 min (87% of participants thought this was the perfect length [Bodde et al. 2024]) and 60 min (90% of $n = 29$ participants liked this length very much [Hilgenkamp and Mann 2024]). Additionally, 93% of respondents liked the frequency of three sessions/week very much or quite a bit (Hilgenkamp and Mann 2024).

Different choices can be made for interventions based on the target audience. As described in Table 1, the MOVE-DS programme targets an audience of individuals with intellectual disabilities (not focusing on individuals with Down syndrome specifically) and uses different themes for their exercise sessions with different exercises and order of exercises every session to keep participants engaged, whereas the Mann Method PT Exercise Program, designed specifically for individuals with Down syndrome, is based on a consistent exercise routine with the same order and a specific exercise progression to align with the preference of individuals with Down syndrome for routines and sameness (McGuire and Chicoine 2021) and to foster confidence and competency.

Additionally, interventions should be multicomponent and include physical activity education and behaviour change techniques which may include education sessions that are separate from the exercise sessions. These education sessions allow interventionists to provide background and/or rationale for the exercises used and recommendations for support needed. At one site, 100% of 29 participants/caregiver dyads thought the exercise session was helpful, and 97% thought the education session was helpful (Hilgenkamp and Mann 2024). Examples of the use of education sessions are provided in Table 1.

5.2 | Theoretical Frameworks Underlying Instructions

The framework for how instructors facilitate participation during class should be grounded in self-determination principles to promote independence for individuals with intellectual disabilities. The three basic psychological needs of self-determination theory are autonomy, competence and relatedness (Deci and Ryan 2008). These elements are embedded in the classes to enhance participation and foster intrinsic motivation within the learning environment by allowing participant choice (autonomous decision making), sequential practice of skills (competence) and social support through peer modelling and instructor encouragement (relatedness). The Social Cognitive Theory (SCT) (Bandura and McDonald 1963) is a second important underlying theoretical framework, which emphasises that people learn new behaviours from observing and interacting with their environment. Strategies grounded in the SCT used in the online exercise programmes include using simple, clear instructions, modelling of exercises and behaviour, tracking and positive feedback on progress, and environmental cues and reminders such as visual charts.

5.2.1 | Specific Communication Strategies

Positive reinforcement plays a crucial role throughout the programme, and effective strategies include providing direct attention (using first name of participant), using clear one-step instructions, maintaining consistent language, providing external versus internal cues and allowing adequate processing time for requests. Additional strategies used by the instructor include using positive corrections whilst giving feedback, a focus on doing it together, using proactive prompts to practice/start exercises (recommended action-oriented phrases are 'Let's...', and 'First..., then...') rather than asking repeatedly 'can you....'. Providing participant choice and opportunities to lead familiar exercises can encourage autonomy in physical activities and facilitate the social component of the programme.

Because intellectual disabilities are heterogenous and individuals experience a wide range of abilities in the communicative, social, cognitive and behavioural domains, it is helpful to get know the participants and become familiar with their unique

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personalities and motivators. This can be accomplished by administering a preference assessment as part of the preparticipation screening. A preference assessment involves a short battery of open-ended questions (i.e., 'What are your favorite upbeat songs? These are songs we will incorporate into our exercise playlist.', 'What are your favorite animals?' etc.) to capture as many motivating factors for the participant as possible (Sherman 2022) (included as Data S1).

Individuals with Down syndrome have distinct learning styles, strengths and cognitive challenges that necessitate special considerations for effective programme delivery. These include a preference for sameness and routine, being excellent visual learners (whereas they experience more difficulty with verbal communication), motivated by positive social encouragement and reinforcement, and the need for more time for processing and for familiarisation and practice (McGuire and Chicoine 2021; Stein 2016). To create an environment conducive to success, the exercise routine needs to be consistent, the verbal and visual cues need to be consistent, and movements need to be practiced over time, gradually progressing in difficulty over the course of the programme. A predictable exercise routine and clear and consistent cueing can significantly enhance successful participation, as it facilitates the development of skills and a sense of mastery, thus increasing confidence. As individuals with Down syndrome are strong visual learners, they benefit from visual aids such as charts, photos and videos.

5.2.2 | Movement Observation and Feedback

As many of the movements and exercises will be new to participants, the instructor should monitor execution and ensure safety. This includes keeping the workout space free of equipment unless needed for the exercise, observing specific movement or compensation patterns due to impairments or areas of pain, and providing individual and tailored feedback to adjust execution. The instructor may need to discuss adjustments with the family so they can provide support in the initial stages. The instructor also monitors for improvements in participation, execution, duration or number of repetitions, and provides specific individual positive feedback (see previous section). Heart rate monitors can be used to inform participants and/or the instructors about the intensity of participation.

5.3 | Intervention Delivery

5.3.1 | Technology Requirements

Successful online delivery of an exercise programme is fully dependent on the supporting technology. These recommendations are critical as they ensure the instructor can safely assess, monitor and instruct participants. Participants and instructors must both have reliable and fast internet connections (preferably 5G or fibre optic), and access to an online, user-friendly platform (e.g., Zoom) that allows for sessions longer than 45 min, integrated audio and recording options, and full body camera views. Research studies generally require this platform to be compliant with laws that protect personal/health information and ensure confidentiality (such as the Health Insurance Portability and Accountability Act), with a business associate agreement (BAA) in place. Those responsible for data collection also require sufficient storage space to record local files for transfer to secure cloud drives.

Adequate lighting is paramount to a good delivery of the instruction, making sure that the participant is in a brightly lit room, and if needed, added lighting for the instructor (such as large ring lights or photo staging lights). One device with a camera is needed on a tripod to allow for full body view of the instructor throughout the session, both whilst standing with arms extended and laying on the floor with arms and legs extended. At least one large screen computer/TV monitor (27″ or larger when class size is >10 participants) is needed to provide a student view for the instructor, large enough to see participants clearly for safety.

Participants need a device (tablet or laptop) with a camera positioned so the instructor can get a full body view of the participant, and the participant can clearly see the instructor on their screen. HDMI connectors can be used to connect smaller devices to a larger TV screen so that the participants can have a larger view of the instructor and fellow participants.

Audio clarity and volume are also important; instructors are recommended to wear wireless headphones with a hands-free microphone so participants can hear instructions clearly regardless of the position of the instructor. Instructors will also need to have a musical library that they can use through the platform to stream for dance sections of the workout, preferably with a range of genres, including favourite songs of the participants, so instructors can tailor the music to be most appropriate and motivational to the specific class.

5.3.2 | Physical Environment Requirements

The instructor needs a space dedicated to the delivery of the programme. This space needs to be big enough to allow for a full body view with arms extended in both standing and laying down positions, so no camera adjustments are needed throughout the session. Instructors may consider gym flooring, in addition to the exercise mat, for additional padding.

Exercise equipment needs to be off camera when not in use, but within reach. See Table 1 for equipment needed for the Mann Method PT-Based Program and the MOVE-DS Program. Because of the increased use for instructions, instructors may consider gym flooring in addition to the exercise mat. Instructors are recommended to wear appropriate footwear (modelling shoes that are recommended for participants) and exercise clothing that allows participants to see foot placement and body positioning through solid coloured clothing and contrast in light/dark between the top half (t-shirt/top) and bottom half (shorts/tights).

5.3.3 | Group Setting

The research groups have successfully provided online exercise programmes to groups of up to 20 participants, but smaller

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groups of up to 10 people are recommended to ensure optimal monitoring, feedback and safety. The small group setting allows for increased participant interaction, the formation of relationships, increased opportunities to work on social skills and creates a consistent familiar community for working out.

6 | Best Practices for Communication

6.1 | Before the Programme

As not all participants have the same level of experience with online platforms, a remote session beforehand is recommended. This gives instructors the opportunity to go over the technical steps to log in to the online platform, the ability to review the intended location for the participant to do the workout, and assist in area setup and suggestions for appropriate camera angles and view of the screen for the participant. If needed, connecting the device to a larger TV might be helpful.

During this session, the instructor can also inquire about any relevant health history, any concerns or restrictions for physical activity and any injuries or areas of pain. This is also the moment to revisit the preference assessment administered during prescreening to further get to know the participant and their family, with regards to interests, favourite music, hobbies, birthday, motivating elements and their regular daily schedule. Asking participants for their favourite songs and artists in advance of the programme will help instructors develop their music playlist. The instructor will convey the expectations for the workout session, which generally include being present for each session a few minutes before start time, wearing appropriate workout shoes and clothing, and sending a note when absent.

6.2 | During the Programme

In the early phase of the programme, the instructor may need increased communication with the family to support a successful set up of the environment and execution of movements. As the participant becomes stronger and more independent, the instructor may need to guide the family on how to decrease support. Instructors may need to send out extra videos to individual participants for challenging exercises, with a more extended demonstration. Throughout the programme, participants should receive a prompt email if they are not present at the start of class with a nudge to join the class. If unexpected absences continue, the instructor should check in with the family to show concern for what is going on and collaboratively come up with a solution (e.g., sending a recording). Throughout the programme, instructors are recommended to reach out to provide timely updates to the families (usually monthly updates and check-ins for 12-week or longer programmes) and to check in with their participation experiences, noticeable changes during and outside of the workout sessions, and any feedback to make the programme more successful for the participant.

6.3 | At End of the Programme

At the end of the programme, the instructors should follow up with the participant and their family in an individual online session to discuss areas of improvement, strengths and ongoing progress, as well as successful elements of the programme, and areas that could be improved upon. Instructors should also discuss opportunities to continue participation in purposeful exercise, and strategies that the family and participant will use to continue progress.

7 | Requirements Coach/Trainer

7.1 | Credentials

All instructors in the included programmes are recommended to hold at least a baccalaureate degree in exercise science, special education or a related field. It is best if they have a background in exercise instruction and prescription, and some familiarity with exercise instruction. Although not required, additional training resources such as the Autism Exercise Specialist Course from ACSM and Exercise Connection and the Inclusive Fitness Specialist Course from NCHPAD and ACSM can provide population-specific training. Instructors will be responsible for the instruction, safety and motivation of the participants. They must undergo a training programme developed and overseen by an expert which includes shadowing current exercise sessions, education on the application of self-determination principles within the community of individuals with intellectual disabilities, and appropriate modifications and progressions for exercise. Specific instructor requirements per programme are described in Table 1.

7.2 | Characteristics

In order to successfully motivate and encourage participants in any exercise programme, instructors must have specific qualities or characteristics. At the most basic level, instructors must be punctual and consistent as individuals with intellectual disabilities thrive on routine and consistency. Instructors must be ready to start the class at the appointed time, arriving 5–15 min ahead of schedule to log in, start the session, set up the music and make sure all audio/visual/recording systems are ready for the class. Instructors must also be attentive to safety and able to monitor individuals and groups whilst leading exercises and promoting safe participation. Instructors must be positive, encouraging and energetic seamlessly integrating the elements of the self-determinism and SCT philosophies into class to build competence, relatedness and environmental interaction. Instructors must have consistent and clear language that effectively instructs and motivates, but is also repetitive and consistent. They must have a consistent cadence through each class and over the course of the programme so exercise instruction and execution is delivered consistently. The importance of this is illustrated by a quote from one of the caregiver/participant dyads: 'We think Coach is the key to the success of this exercise program.' … 'Her enthusiasm is contagious and makes exercise FUN! She is able to watch ALL the participants carefully and offers constructive comments to help each person perform the exercises to the best of their abilities. She is patient, kind, and so generous with her time. She establishes deep connection with every participant.' (Hilgenkamp and Mann 2024).

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8 | Conclusion

Remote delivery of exercise for people with intellectual disabilities has the potential to reach individuals in a variety of settings, including their homes, day programmes or in group living settings. Delivering exercise to groups of individuals in these settings may reduce the burden on disability service professionals to provide physical activity programming to their clients. Whilst all exercise programmes need to be tailored to the specific needs of the target population or research question, the above recommendations can aid researchers in developing and implementing remote exercise programmes for people with intellectual disabilities.

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Consent

All studies reported on followed the US Federal Policy for the Protection of Human Subjects, were evaluated by the Institutional Review Board and all participant/caregiver dyads have provided written informed consent prior to inclusion of the studies (NCT04048759 and NCT04854122).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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