Interventions to improve physical activity in daily life of people with intellectual disabilities. Detailed results presentation of a scoping review.

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Pictures from Stefan Albers, Atelier Fleetinsel, 2013

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förges-Network

The scoping review was carried out by the research project 'förges 3'. It belongs to the consortium „User-oriented care: Promotion of health in the context of chronic diseases and care dependency", called förges network.

The research network is based on the collaboration of five non-profit welfare organizations in the federal state of North Rhine-Westphalia, the School of Public Health (Bielefeld University), and the Faculty of Business and Health, University of Applied Sciences Bielefeld (FH Bielefeld). The network runs from April 2018 to March 2021 and is funded by the Stiftung Wohlfahrtspflege (http://www.sw-nrw.de/home/). The network is coordinated by the Bielefeld University.

In five projects scientific based strategies for the promotion of health and self-management support are developed, pilot tested and validated. The projects are framed by cross-sectional analyses (förges Q).The major research objectives are:
- Enabling user-orientated care, i.e. a needs-based care that allows maximum quality of life.
- Maintaining autonomy despite chronic conditions by strengthening health literacy, self-management, and user participation – here regarded as nursing task.

https://www.uni-bielefeld.de/(en)/gesundhw/ag6/projekte/foerges.html

Abstract

Today, low levels of physical activity are a major health problem for society and are associated with an increased risk for chronic diseases especially by people with intellectual disability. To our knowledge, target group concepts to promote physical activity addressing daily life are rare. Therefore, the aim of our research project is to develop, test and validate a multi-modal target-group-oriented intervention. This intervention will promote a physically active lifestyle by promoting health-related literacy, physical activity-related health competence and self-efficacy. The first step of the project is to review the current state of interventions promoting physical activity in people with intellectual disability with a focus on daily life activities. This article describes the approach and the findings of the conducted scoping review.

In general, 33 articles were included. They were sorted by overviews, systematic reviews, studies, and curriculum. For a good overlook and comparison data were mapped for each category, except the single curriculum. Likewise, for all categories, the results were summarized via a qualitative thematic analysis in a narrative format. For this, we identified relevant statements in the articles according to our research questions: a) How is the motivation of the participants discussed? b) How are the needs of participants integrated in the intervention? c) Are competencies/physical requirements for physical activity of users analyzed and if so, how? d) How are the interventions evaluated? Categories were added if we identified them as important for the conceptualization of our intervention.

This report has three goals:

a) It is a tool-box (pool of ideas) including basic concepts and tested strategies for the conceptualization of our own intervention, taking into account information about physical activity related barriers and facilitators.
b) To give detailed information about the data our intervention will be based on.
c) To provide an overview about the current state of knowledge.

Content

1) Introduction

1.1 Background

Today, low levels of physical activity are a major health problem for society and are associated with an increased risk for chronic diseases (Guthold et al. 2018). Physical inactivity (lack of physical activity) has been identified as the fourth leading risk factor for global mortality (6% of deaths globally) (WHO 2009). Moreover, the WHO estimates that physical inactivity is a main cause for e.g. approximately up to 25% of breast and colon cancers, 27% of diabetes and approximately 30% of ischaemic heart disease burden" (WHOa).

The World Health Organization (WHOa) defined physical activity

> "as any bodily movement produced by skeletal muscles that requires energy expenditure. ... The term "physical activity" should not be mistaken with "exercise". Exercise is a subcategory of physical activity that is planned, structured, repetitive, and purposeful in the sense that the improvement or maintenance of one or more components of physical fitness is the objective. Physical activity includes exercise as well as other activities which involve bodily movement and are done as part of playing, working, active transportation, house chores and recreational activities."

Recommendations from the WHO (no year mentioned, b) for physical activity are as follows:

> "Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity[1] throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity".

Compared to the general population diseases occur more frequently and often earlier in lifetime in people with intellectual difficulties (PWID) (e.g. Mair & Offergeld 2014, Patja et al. 2008, Mac Rae et al. 2015, O'Leary et al. 2018). A positive effect of physical activity on prevention and health preservation has been proven (Bergström et al. 2013, van Schijndel-Speet et al. 2017). By promoting physical activity, health literacy and physical activity-related health competence (e.g. Sudeck& Pfeifer 2016) the risk of diseases can be minimized, existing diseases can be managed better and the course of a disease can be influenced positively (Bruland et al. 2019). However, due to reduced cognitive abilities, communicative and reading-writing skills, people with intellectual disability are mostly not considered in concepts and have less

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[1]Aerobic physical activity is done for longer periods of time – mostly defined as longer than two minutes as the body adjusts to the activity and begins to supply sufficient oxygen to the muscles.

access to programs promoting physical activity (Emerson et al. 2014, Hasseler, 2014). In addition, there is a lack of access to health-related resources, compared to the general population (Hasseler, 2014). To our knowledge, target group concepts addressing daily life are rare and above that, there is no intervention integrating the perspective of participants during the development process in Germany (Bruland et al. 2019).

1.2 Research project förges 3

The project förges 3 tries to close this (research) gap. Therefore, the aim is to develop, test and validate a multi-modal intervention with the participation of future users in a demand oriented and target-group-oriented manner. The intervention will promote a physically active lifestyle by promoting health-related literacy, physical activity-related health competence and self-efficacy. It is carried out in cooperation with the 'LebenshilfeBrakelWohnenBildungFreizeitgGmbH', which is an integration assistance service with several residents and outpatient offers for people with intellectual disability. The project will be performed in three steps:

1. Conduction of a scoping review about interventions to promote physical activity in people with intellectual disability;
2. Analysis of individual movement experiences as well as desires and needs of future intervention users (people with intellectual disabilities) regarding the promotion of their own individual physical activity behaviour via methodological triangulation (target group adapted interviews, participatory observation, explorative online survey for staff and document analysis – conducted in 2019);
3. Development, test and validation of an intervention in cooperation with the future users.

An article about the project, which is also describingthe idea of the planned intervention has been published (Bruland et al. 2019).

1.3 Aim of the scoping review

This scoping review is a basis for our intervention development. In general, a scoping review is well suited when the purpose is to provide an overview about existing literature, to clarify concepts or to investigate how research is been conducted (Munn et. al. 2018). The aim of this scoping review is to map the state of research as well as to systematically describe and present the results. In detail, it is about identifying and clarifying important concepts, processes and modes of action. Consequently, the results will inform the conceptualization and development of the planned intervention.

The report has three goals:

a) It is a tool-box (pool of ideas) including basic concepts and tested strategies for the conceptualization of our own intervention, taking into account information about physical activity related barriers and facilitators.

b) To give detailed information about the data our intervention will be based on.

c) To provide an overview about the current state of knowledge.

1.4 Presenting structure

The scoping review was conducted using methodological guidelines from Arksey and O'Malley (2005) and Levac et al. (2010). The present scoping review consists of five steps (Arksey and O'Malley 2005):

- Identification of the research question;
- Identification of relevant studies;
- Study selection;
- Charting data; and
- Collating, summarizing, and reporting results.

We will add the chapter 'Identifying the implications of the study findings for our research' (concerning to Levac et al. 2010) in order to present, how the results will be used for our research project.

2) Identification of the research question

We are referring to the WHO-definition of physical activity described above, and are particularly interested in activities, that can be implemented in daily life (routines) by people with intellectual disabilities, like using stairs instead of taking an elevator, deciding to walk instead of using a bus (see the inclusion/exclusion criteria below). According to this, the primary research question is:

„What is the state of the art in interventions to promote physical activities addressing daily life situations for people with intellectual disabilities?"

This question should lead to an overview of interventions that are suitable with regard to our research interest. Secondary research questions focus on:

- How is motivation of the participants discussed?

  (In general, but with a main focus on how participants are motivated to stay physically active during the intervention.)

- How are the needs of participants integrated in the intervention?

   (Main focus on participatory approaches or how participants can share their experiences/needs and can contribute to the intervention and its modification.)

- Are competencies/physical requirements for physical activity of users analyzed and if so, how?

   (Are restrictions of the participants recorded and how are they taken into account?)

- How are the interventions evaluated?

3) Identification of relevant studies

A systematic approach was employed to identify relevant articles. Six databases were searched by using Englisch search terms from publication dates 01/01/1998 up to the 11th October 2018. We decided to consider articles ten years before the UN Convention on the Rights of Persons with Disabilities came into force. We assume that attitudes towards people with intellectual disabilities have changed after the adoption of the Convention and that there are to be found more projects that are in line with our participatory approach to research. The following databases were searched:

- Medline via PubMed
- CINAHL via EBSCOHost
- PsycInfo via EBSCOHost
- Eric viaEBSCOHost
- Web of Science

Additionally, one database was searched using German search terms (PSYNDEX via EBSCOHost). Furthermore, reference lists of included review articles were searched manually (DB) for potentially relevant publications. The search terms were generated by examining terminology used in current literature about people with intellectual disability and physical activities (see table1 for English and table 2 for German).

Table 1: English search terms

Target group	Activity and health related behavior	Mobility	Antonym
intellectual* disab* or learning disab* or mental* deficien* or mental* disab* or mental* handicap* or developmentaldisab* or intellectual	physical activit* or physical action* or (habitual/physical) exercis* or exertion or"Physical fitness" or Health* behav* or behav* change*	Move*or mobil*or agilit*or flexibil*	physical inactivity or immov* or immob*

handicap* or mental* retard* or mental* subnormal* or down syndrome			

Table 2: German search terms

Target group	Activity and health related behavior	Mobility	Antonym
Geistig* Behinderung or intellektuell* Behinderung	Bewegung OR körperl* Aktivität	No search tearms	No search terms

We combined search terms using Boolean operators and used wildcard characters in order to cover all spelling variations of the search terms. As an example, the following algorithm has been used in PubMed:

((intellectual* disab*[Title/Abstract])OR(developmental disab*[Title/Abstract])OR(learning disab* [Title/Abstract])OR(mental*deficien*)[Title/Abstract])OR(mental* disab*[Title/Abstract])OR(mental* handicap* [Title/Abstract])OR(intellectual handicap*[Title/Abstract])OR(mental* retard* [Title/Abstract])OR(mental* subnormal* [Title/Abstract])OR(down syndrome[Title/Abstract]) ((AND (physical activit*[Title/Abstract])OR(physical action*[Title/Abstract])OR((habitual OR physical) exercis*[Title/Abstract])OR(exertion[Title/Abstract])OR("physical fitness"[Title/Abstract])OR(health* behav*[Title/Abstract])OR(behav* change*[Title/Abstract])OR(physical inactivity[Title/Abstract])OR(immov*[Title/Abstract])OR(immob*[Title/Abstract])))

By searching the databases, we identified 3,190 articles. We (DB, TS and ÄDL) decided that the number of identified articles would be sufficient for the feasibility of our purpose (following Levac et al 2010), also taking into account project resources.

4) Study selection and data screening

4.1 Study selection

For the purpose of this search, the following criteria were used (see also figure 1):

Figure 1: Inclusion and Exclusion criteria.

Exclusion criteria:
- Sports/activity programs e.g. football training
- Studies measuring physical activity levels
- Studies describing physical activity behavior (e.g. barriers but no intervention)
- Medical/genetic examinations in connections with physical activity
- Studies focusing on instruments for measuring physical activity

Inclusion criteria:
Interventions and programs with the aim of promoting physical activities in daily life

Inclusion of studies focusing on strategies for integrating physical activity in daily routines and obtain lifestyle changes (sustainability)

In detail, inclusion criteria were:

- people with intellectual disability,

- concepts and intervention programs to promote physical activity (related to daily life / routines),

- adults ($\geq$ over 18 years),

- English and German language,

- published from 01/01/1998 up to search date,

- all relevant studies regardless of their design and quality, including overviews and systematic reviews.

Exclusion criteria were:
- articles not involving people with intellectual disability,

- main focus on other diseases e.g. epilepsy in people with intellectual disabilities (too specific),

- focus on children and adolescents under 18 years,

- sports/exercises/fitness programs, which do not focus on activities for daily life or lack any direct approaches to lifestyle changes, e.g. football training, fixed exercise programs as training units,

- main focus on medical examinations in connection with physical activity (e.g. cardiovascular exercises) or validation studies of assessments/outcome measures,

- epidemiologic studies describing physical activity levels,

- studies not describing promoting physical activity or any intervention

- studies published before 1998,

- any other language than English or German,

- conference abstracts,
- study protocols of now published studies (see e.g. Pérez-Cruzado & Cuesta-Vargas 2013 & 2016).

4.2 Data screening[2]

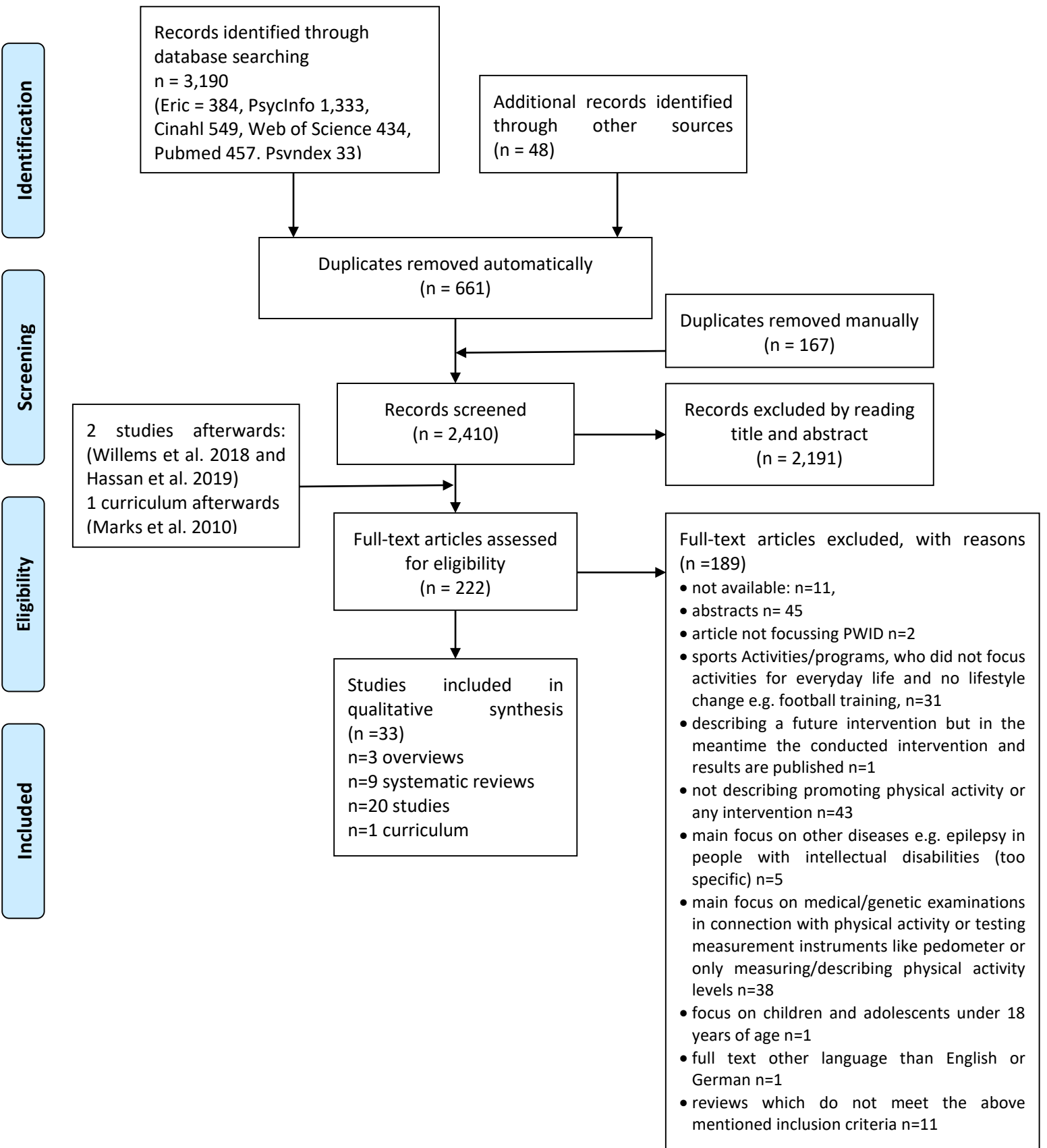Data screening was conducted as follows (see also figure 2 next side):

Identified literature from the databases was imported to the reference management software CITAVI 6 (n=3,190) and complemented manually by the additional records identified through other sources (n=48). Those are mainly from in the past conducted literature reviews from our institute with a different attention focus / research questions. Others were found randomly by searching for articles e.g. similar articles have been proposed. Duplicates were removed automatically and manually which resulted in a total of 2410 remaining articles. Two researchers (DB, TS) independently screened titles and abstracts of the retrieved records for inclusion or exclusion. After title and abstract screening 222 articles remained. Whenever it was unclear if an article should be included, the fulltext was retrieved and the eligibility criteria were checked again independently. We retrieved the full-text articles and same researchers independently rated each as relevant or irrelevant. Disagreements were solved by a third researcher (ÄDL). By agreement among all researchers three studies which met the inclusion criteria were included afterwards, for the reason that they may contain relevant information from them could be very relevant: two reviews were published after our search date (Hassan et al. in 2019 and Willems et al. in November 2018), the third one is a curriculum and therefore was not included in the data base assessment. Finally, full text screening resulted in a total of 33 included articles for analysis.

One researcher (DB) searched the literature list of systematic reviews and overviews to find articles about interventions not found so far and checked them for inclusion criteria. No more articles had to be added. The identified articles were already included or did not meet the inclusion criteria. The article of Willems (2017) doesn't have a literature list of the included studies, thus, the studies could not be checked.

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[2]Following lists are attached: Attachement No. 1: all studies after removing duplicates; Attachement No. 2 excluded titles with reasons.

Figure 2: Prima Flow Chart

Records identified through database searching
n = 3,190
(Eric = 384, PsycInfo 1,333, Cinahl 549, Web of Science 434, Pubmed 457. Psvndex 33)

Additional records identified through other sources
(n = 48)

Duplicates removed automatically
(n = 661)

Duplicates removed manually
(n = 167)

2 studies afterwards: (Willems et al. 2018 and Hassan et al. 2019)
1 curriculum afterwards (Marks et al. 2010)

Records screened
(n = 2,410)

Records excluded by reading title and abstract
(n = 2,191)

Full-text articles assessed for eligibility
(n = 222)

Full-text articles excluded, with reasons (n =189)
- not available: n=11,
- abstracts n= 45
- article not focussing PWID n=2
- sports Activities/programs, who did not focus activities for everyday life and no lifestyle change e.g. football training, n=31
- describing a future intervention but in the meantime the conducted intervention and results are published n=1
- not describing promoting physical activity or any intervention n=43
- main focus on other diseases e.g. epilepsy in people with intellectual disabilities (too specific) n=5
- main focus on medical/genetic examinations in connection with physical activity or testing measurement instruments like pedometer or only measuring/describing physical activity levels n=38
- focus on children and adolescents under 18 years of age n=1
- full text other language than English or German n=1
- reviews which do not meet the above mentioned inclusion criteria n=11

Studies included in qualitative synthesis
(n =33)
n=3 overviews
n=9 systematic reviews
n=20 studies
n=1 curriculum

Identification

Screening

Eligibility

Included

5 Charting the data

Data analysis was conducted by three researchers (DB, NN, ÄDL). First, the included studies were categorized as follows:

a) Overviews

- which present an overview of literature; the search process to identify relevant literature is not documented

b) Systematic reviews

- which identify literature in a systematic way and use explicit methods to select, extract and analyze it

c) Studies

- which present an intervention, its background, development, implementation and/or evaluation

d) Curriculum

- which include a planned sequence of instruction

The data were mapped for each category, except the curriculum. In order to get a good overview and options for comparisons, the identified literature was coded.

Overviews were coded to:

- author,
- publishing year,
- country,
- research questions / aim of the overview,
- inclusion and exclusion criteria,
- no. of included studies,
- main content,
- results, and
- limitations.

In the same way reviews were coded and the following codes were added:

- databases,
- search terms as well as
- study/intervention characteristics of included studies.

[9]

For coding the studies, we took over the following categories, that were also used in included reviews:

- author,
- year,
- country,
- sample (inclusion criteria),
- setting,
- type of physical activity,
- type of intervention,
- intervention description,
- length of programme / frequency / duration,
- theoretical basement,
- provider,
- physical activity outcome measure,
- results,
- discussion,
- limitations.

Due to our special interest, we added the aspects motivation (how is motivation maintained?), needs of participants (how are needs of participants considered?) assessment of competencies/physical requirements (how are competencies and physical requirements of the participant taken into account?), as well as PA outcome measures. In the process of analyzingwe found out, that most articles refer to the same interventions. We therefore combined them for the reason that it is sufficient to describe the content and approach of an intervention (e.g. aim, duration, setting, description of intervention elements) once.

All tables are in attachment 3.

6 Collation, summarization, and report of results

6.1 Structure

For all categories the results were summarized via a qualitative thematic analysis in a narrative format. For this, we identified relevant statements in the articles according to our secondary research questions:

- How is motivation of the participants discussed?

(In general, but with a main focus on how the participants are motivated to stay physically active during the intervention.)

- How are the needs of participants integrated in the intervention?

  (Main focus on participatory approaches or how participants can share their experiences/needs and contribute to the intervention and its modification.)

- Are competencies/physical requirements for physical activity of users analyzed and if so, how?

  (Are restrictions of the participants recorded and how are they taken into account?)

- How are the interventions evaluated?

Results according to the research questions as well as relevant results for our research project were presented for each category. That means, we added categories if we found them important for our own intervention development. First, we summarized the main results of overviews and systematic reviews, second, of included studies, third, of the curriculum. We would like to remind that this report is a tool-box (pool of ideas) with basic concepts and strategies for our own development. Therefore, we did a detailed results presentation; for example, we tried to avoid data loss and used direct quotations when appropriate. A quality assessment of included studies was not conducted, because included reviews described challenges for quality assessment in research with people with intellectual disabilities adequately (see 6.3 chapter Results of reviews and quality of studies). Due to the heterogeneity of included studies in terms of interventions and outcomes, statistical analysis or meta-analysis was also not conducted.

6.2 Overviews

Article overview

There are three overviews, all conducted in Western Countries (USA/Canada (2), Israel (1)). All of them are published in the same period (from 2006 – 2008). Two of them are from the same author, but have a different research question (see attachment No. 3). Stanish et al. (2008) states that people with intellectual disabilities (PWID) were normally not included in large-scale population studies and received relatively less attention in health promotion efforts or physical activity campaigns (but she does also argue that in 2001, the U.S. Surgeon General held a conference to address health disparities in PWID and set an agenda to reduce these disparities). For this reason, there is a lack of information about health indicator segments for PWID.

Nevertheless, Stanish et al. (2006) and Lotan (2007) present important physical acitivities for PWID:

Stanish et al. (2006):	Lotan (2007):
„Major sources of physical activity for adults with ID[3]":	„The positive contributions that exercise programs entail have led to the implementation of various intervention programs for individuals with ID. These programs included:"
Walking* and cycling for transport	Stair climbing
Chores and work	Walking, running, stretching, and aerobic exercises
Dancing	Floor and flexibility exercises
Special Olympics	A mile run, use of a rowing machine, weight lifting, bicycle training
	Treadmilltraining
	Walking

*"Walking for transport was by far the most prevalent form of physical activity, but studies suggest the intensity may not be sufficient to meet the minimum recommendations to achieve health benefits" (Stanish et al. 2006).

How is the motivation of the participants discussed?

Stanish et al. (2006) discuss that PWID „are highly motivated to engage in activity as a social outlet, similar to the nondisabled." However, the barriers for PWID are higher than in the general population (see below).

During the intervention motivation was addressedby ribbons and medals received through Special Olympics (Stanish et al. 2006), token systems and verbal encouragement (Stanish et al. 2008). One of the mentioned interventions shows, that some programs are not performed in the long run by the participants: „A core group of individuals continued to do aerobics with the videos for a month but the level of active engagement was slightly reduced. Both articles supported that adults with ID will be active if provided with enjoyable opportunities like aerobics, but the direct involvement of others (i.e. staff, families) is needed to facilitate participation and promote adherence" (Stanish et al. 2008). Stanish et al. (2006) describes: „This is a concern because reliance on this type of external reinforcement may not be conducive to activity maintenance."

The staff plays a very important role for motivation: „Lack of staff motivation to promote physical activity, a lack of physical activity counseling, and high client-to-staff ratios have all been reported as constraints to participation. Individuals with MR[4] articulated that caregivers,

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[3]ID = Intellectual disabilities
[4]MR = mental retardation a synonymous word for intellectual disability, but it is offensive, therefore it is only used in direct quotations

teachers, coaches, and medical personnel rationalized, enabled, and oftentimes encouraged sedentary behaviors. Independent participation in activity was largely discouraged by reinforcing fears and the need for constant supervision. Persistent messages were that participants should not overexert themselves or "overdo it." These negative messages were well-intentioned efforts to protect seemingly vulnerable individuals but the outcome was that participants with MR developed perceptions of disempowerment, physical fragility, overreliance on supports, and incompetence with regard to being physically active" (Stanish et al. 2006).

The question arises (which cannot be answered here): how much support is necessary and how much self-determination is possible in an intervention to promote PA?

How are the needs of participants integrated in the intervention?
Little is found. Only Stanish et al. (2006) mention that due "to the general description of environmental determinants there have been few attempts to study social and environmental factors that influence physical activity from the perspective of the individual with MR."

Are competencies for physical activity of users analyzed and if so, how?
Lotan (2007) gives information focussing on physical requirements. he states that it is important to consider and check the health status and physical fitness of individuals before engaging in physical activity.

„Abnormal energy expenditure and substrate utilization can also be present in individuals with DS. Therefore, in order to avoid lowering already inadequate intakes of several vitamins and minerals, physical exercise programs for individuals with DS[5] should combine a balanced diet with vitamin and mineral supplementation" (Lotan 2007).

How are the interventions evaluated?
Stanish et al. (2006) describes that there is no „gold standard", and suggests physical activity assesments, that demonstrate acceptable validity and reliability:

- Doubly labeled water (calculates the energy consumption via the carbon dioxide tax),
- Self reports (diary/log, recall questionnaire, quantitative history, and global self-report) ,
- Motion Sensors / accelerometers (sensors measure limb or segment acceleration as an index of human movement and provide a direct, objective measure of physical activity in field-based settings,
- Pedometers (measure steps and distance in response to vertical acceleration, but it is important to note that the devices are not as sophisticated as accelerometers),

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[5]Lotan focus on people with Down Syndrom (DS), which belongs to intellectual disabilities.

- Heart rate monitors,
- Direct observation.

„There are advantages and disadvantages associated with each method and those most commonly used to examine naturally occurring physical activity behavior are self-reports, activity monitors, and pedometers" (Stanish et al. 2006). Stanish et al. (2006) further noted that only pedometers have been examined for validity for people with ID, the use of multiple methods enhances accuracy and multiple measures allow „a more comprehensive understanding of physical activity behavior since single methods are limited in scope. Combined use of objective (motion sensors or pedometry) and subjective (self reports) instruments will likely provide the best assessment of both the quantity and quality of movement in people with MR" (Stanish et al. 2006).

Concerning the evaluation Stanish et al. (2006, 2008) also point out:

- "There has been only one study that actually used a comparison group to assess the magnitude of difference in physical activity between those with and without MR" (2006).

- "The use of proxy respondents as data sources and a 4-week activity recall also calls into question the validity of these findings for reasons previously discussed" (2006).

- "While many interventions have been short-term and some have methodological shortcomings (e.g. small sample size), it is beneficial to review the findings of previous work to guide future research and practice" (2008).

Barriers and facilitators

In addition, the overviews describe barriers and facilitaing factors for physical activity. Lotan (2007) mentions limitations set by the physical environment (residence type), by personal characteristics on participation in exercise programs (physical requirements), and by close human environment (family/caregivers). Stanish et al. (2006) describe five categories of potential barriers and facilitating factors of physical activity: demographic and biological factors, psychological/cognitive/emotional factors, behavioral attributes and skills, social and cultural factors and physical environment factors.

Stanish et al. (2008) point out barriers for physical activities in PWID:

„Lack of energy, too difficult, and boring were the most commonly reported cognitive-emotional barriers by people with Down syndrome while caregivers perceived that lack of interest, lack of energy, and too lazy to be the most dominant barriers. In regards to access, the

main barriers reported by individuals with Down syndrome were no transportation, costs too much, and no one to show how to exercise. Caregivers agreed that transportation and cost were the significant barriers to access."

„The staff groups reported that their ability to provide physical activity opportunities to the individuals with ID that they serve was limited by many variables. The barriers noted were 1) limited options and choices for leisure in the community for people with ID, 2) limited financial resources required for services like transportation and staff, 3) staffing ratios that precluded the adults with ID from having the support that they required to engage in an activity, 4) limited financial resources of people with ID required for program/facility fees and transportation, and 5) unclear policy guidelines for residential and day program service provision."

Recommendations to promote physical activity

The authors' recommendations are quoted verbatim:

Stanish et al. (2006): „Including physical activity into the daily routines of people with ID can also promote health. For example, increasing walking intensity (i.e. speed) to and from work was proposed as a strategy to increase appropriate physical activity. Reducing sedentary time, like television watching, is also essential to health promoting physical activity. Staff and family members can facilitate activity opportunities to reduce the need for paid instructors and high levels of supervision in the community."

Lotan (2007): „To prescribe a beneficial exercise program properly, one must have a basic understanding of the elements of exercise physiology and energy metabolism, as well as of the cardiovascular, respiratory, and musculoskeletal responses to exercise and training. Such specific knowledge is mandatory when constructing an appropriate activity program for any population. The basic elements all sport activities should entail are cardiovascular exercise, strength training, balance, and flexibility. … [But not] Flexibility because of the hypermobility and joint laxity that is common in DS, it is not a recommended activity for this population. … A broad habilitational concept should take into account for the physical development of the individual with DS, but also the person's social, emotional, and cognitive growth."

Stanish et al. (2008) state that there is evidence, that physical activity has a positive influence on flexiblity, but also argue, that people with Down Syndrom may respond differently to exercise trainings.

Stanish et al. (2008): "Educational plans should accompany direct activity programs so that people have both the knowledge and the skills to pursue active lifestyles. Even more

importantly, physical activity promotion must involve care providers. If care providers are not aware of the benefits of physical activity and do not have the skills to assist people with ID then it is unlikely that efforts will be sustainable. … It is thought that individuals with ID are not motivated to seek out opportunities to be physically active, therefore, reinforcement strategies and high supervision have typically been used in efforts to promote activity. It is true that family members, residential care providers, employers, and/or other individuals that support people with ID will play a role in identifying opportunities to engage in activity and assist with participation. Therefore, an important step toward improving health behaviors is ensuring that care providers have the knowledge, skills, and resources to facilitate healthy living."

Guidelines are also presented as a check list, see table 3.

Table 3: Guidelines for physical acitivity programmes in people with intellectual disabilities.

„Guidelines for exercise programs for individuals with DS should be" (Lotan 2007):	„The following strategies are examples that could be considered when implementing programs for people with ID" (Stanish et al 2008):
Collect pre-exercise medical data on each participant in order to evaluate contraindications and precautions when initiating the program.	Include motivational strategies and positive reinforcement.
Obtain physician consent.	Include low to moderate intensity activities such as walking.
Take into consideration the effects of medications on the body in relation to exercise.	Ensure that the activity is fun and involves social interaction.
Create a multidimensional activity program that entails endurance, strength, and balance optimal for health and functional benefits.	Involve participants in activity selection and decision making.
Make the program fun to participate in.	Select activities that are age-appropriate.
If exercise machines are involved, label them with pictures and provide verbal encouragement.	Conduct programs in community-based environments where there is opportunity for inclusion (but consider participant preferences).
Provide augmented constant supervision.	Be prepared to modify activities to accommodate all abilities.
Ensure constant monitoring of heart rate through exercise duration.	Monitor progress and set activity goals. and acting as role models; considering
Start the program with light activity that is enjoyable and pain free.	
Provide more visual guidance than verbal instruction.	
Incorporate motivational techniques (i.e., token reward system) to improve adherence.	
Gradually elevate the program's level of intensity.	

Construct a follow-up program, teaching the clients themselves to record their own information to improve long-term adherence and empowerment.	
Ensure an emergency procedure plan for all programs, especially community-based programs. Make socially acceptable elements in the program.	

6.3 Systematic reviews

<u>Article overview</u>

9 systematic reviews were found, all conducted in Western Countries (USA (3), USA/Canada (1), Australia (2), Netherlands (2), Scotland (1)). Six of them are published after 2017, and three from 2011 up to 2014.

The most extensive search was done by Pitchford, Dixon-Ibarra and Hauck (2018). Their scoping review has the aim to body the current state of physical activity research in people with intellectual disability (included articles from 2000 to 2014). Overall, they found 362 studies related to physical activites for people with intellectual disabilities (PWID). Pitchford et al. (2018) used the five phases of the "Behavioral Epidemiological Framework" to characterize and analyze the identified articles. For our interest, only phase 4 and 5 are taken into account ("studies directly intervening to change physical activity behavior or translating intervention into community-based programming"). Only 34 articles were coded in these two phases, however, more than a quarter of them do not address adults (but people under 18 years old). Pitchford et al. (2018) discuss that international and translational research was limited in its search, but also indicate a progress within the field of health promotion for people with intellectual disability. In 2017, Temple et al. state that interventions focusing on increasing physical activity and documenting these changes among adults with ID[6] are a fairly recent phenomenon. This could be the reason why systematic reviews were mainly published in the last years.

Included reviews focus on the following topics:

a) A scoping review from Pitchford et al., content is mentioned above.
b) Four reviews analyzing the strength of evidence on the effectiveness and feasibility of programs, strengths and weaknesses of interventions as well as characteristics of interventions (Bartlo & Klein 2011, Brooker 2014, Temple et al. 2017, Hassan 2019).

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[6] ID = Intellectual disabilities.

c) Heller & Sorensen (2013) focus on health promotion for a special age group: adults with a main view on aging with ID[7]. The article reviews the research on health promotion interventions, including physical activity interventions, health education and mixed approaches and screening services.

d) Harris et al. (2018) analyze multi-component weight management interventions for adults with ID and overweight/obesity and include programs to promote physical activity.

e) Willems et al. (2017 and 2018) focus on Behaviour Change Techniques (BCTs) and the International Classification of Functioning, Disability and Health (ICF-model) in lifestyle change interventions for PWID.

Notes on the categories above:

To b) The inclusion criteria and the orientation of the questions vary between the systematic reviews e.g. while Hassan et al. (2019) only consider RCTs, Brooker et al. (2014) consider all peer reviewed articles regardless of the research design. The results also differ between the included reviews. Our main interest is not a comparison of the studies, but to find points of reference for our research questions. Therefore, we focus on hints and recommendations for our intervention development.

To c) Heller & Sorensen (2013) indicate that "although this review aims to explore health promotion in the context of aging, none of the included studies were limited to older adults, though a few focused exclusively on adults in middle age and older." The systematic review found positive effects of physical activity interventions, mixed approaches (e.g., inclusion of health education) and screening services on health outcomes of people with intellectual disabilities (for more details see attachment 3).

To d) Harris et al. (2018) give good hints for designing physical activity interventions, but the discussion und conclusion chapter are limited to the topics of weight management, to the small number of identified studies and to the restricted generalizability to all adults with intellectual disabilities. Only one included study in this review the participants achieved physical activity recommendations to the WHO (for more details see attachment 3).

The following interventions were included in the reviews, listed here by way of example:

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[7] Heller & Sorensen use the term developmental disabilites as a synonym for intellectual disabilities in their review.

>Walking, bicycling, ergometry, resistance training of upper body and/or lower body, stepping activities, balance activities, dancing, plyometric activities, weigth bearing games, stretching, recumbent stepper, elliptical trainer rowing and health education classes, video aerobic dance program, healthy lifestyle change program, progressive resistance training, cycling and treadmill training.

Harris et al. (2018) distinguish three types of interventions: 1) A structured format of physical activity incorporated as part of an intervention (e.g. once per week, aerobic based activities, strength/muscular endurance activities and stretches to increase flexibility), 2) lifestyle physical activity (walking and activities that can be done at home such as calisthenics e.g. Jumping Jacks), and 3) health education approaches.

How is the motivation of the participants discussed?

Bartlo & Klein (2011) "found that the biggest impact of self-directed approach was that people not initially involved in the activity program wanted to join after observing those in the program." Other statements could not be found.

In which way are the needs of participants integrated in the intervention?

Willems et al. (2018) mention that "the current lifestyle change interventions are not optimally adapted for people with intellectual disability. This is in line with a previous review wich found that carer led health promotion interventions for people with intellectual disabilities were either ineffective or insufficiently tailored to the needs of people with intellectual disabilities".

Are competencies for physical activity of users* analyzed and if so, how?

It is not mentioned in the reviews. However, e.g. Bartlo and Klein (2011) refer to fitness tests to have data for comparison.

How are the interventionsevaluated?

(Only hints that seemed relevant to our research aim are listed here).

Bartlo & Klein (2011) report about the useof the Quality of Life questionnaires in several studies (but with different measures in the studies). Booker et al. (2014) mention the use of the International Physical Activity Questionnaire Short Form (IPAQ-S). It is argued that "subjective measures that were used (for example, the IPAQ-S) were … problematic; the IPAQ-S has been found to be valid and reliable in numerous populations, but has only been found to have limited agreement between objective measures of PA."

Temple et al. (2017) prefer the use of motion sensors (accelerometers and pedometers), in order to receive valid data. However, Booker et al. (2014) discuss in general the low compliance rate

regarding the use of accelerometers, drawing attention to the problem that participant's difficulties that arose were not considered.

Further, interviews and self-reported physical activity are applied for evaluation. However, it is also discussed by Booker et al. (2014) that "difficulties arise with recall, abstract concepts of intensity and duration of PA, and if completed by proxies, the ability of carers to accurately complete the survey. Relying on proxy respondents is not ideal as it may not be a true representation of the participant's views. Alternative methods to surveys to measure PA may be using qualitative methods (i.e. in-depth interviewing or participant observation) or alternative data collection tools (i.e. picture surveys)."

While Temple et al. (2017) name systematic observation as a possible tool for evaluation (noting that it is very labour intensiveand less suitable for larger studies), Willems et al. (2017) suggestcase series: "A case series is a study that collects observations on a series of individuals, receiving the same intervention. These observations are made before and after an intervention, with no control group". This seems to be very labour intensive and less suitable for larger studies, as well.

Results of reviews and quality of studies

The results in the included reviews are very heterogeneous, show different effects and vary in success. For example, Hassan et al. (2019) conclud: „Our study showed that the body of evidence was small, with only nine randomised controlled trials having investigated the effectiveness of interventions to increase physical activity for individuals with ID. The majority of the trials (six trials) found no differences between groups that suggests the experimental interventions that have been evaluated are no more effective than the control interventions. Only three trials found positive effects on physical activity."

However, in general, the quality of studies is rated and methodological problems are reported. We quoted the statements from the different reviews below:

Heller & Sorensen (2013): „Although as a whole the studies reviewed here show positive results of health promotion interventions, the research has many limitations. Few of the studies targeting physical activity and nutrition health education and activitics included strong research designs, sufficient sample sizes, and long-term follow-up. Across the three types of studies, there is little research on the long-term impacts of the interventions or on short or long-term changes in health status."

Brooker et al. (2014): "However, these results are based upon a small number of studies mostly of a pre-post-design with small sample sizes. None of the measures used in the studies reviewed have been demonstrated to be valid or reliable in people with intellectual disability and, importantly, findings lacked follow-up data to determine the impact of interventions in the long term".

Willems et al. (2017): „Heterogeneity is also found for multiple study characteristics, like levels of disability, setting of the interventions, the targeted populations and the aimed lifestyle change (nutrition or PA, or both PA and nutrition)."

Williams et al. (2018): „Several methodological problems, such as small sample size, short intervention duration, lack of follow-up and loss of participants during the intervention resulting in incomplete outcome data."

Hassan et al. (2019): "None of the included trials were assessed to be at low risk of bias – all of the trials were rated as high risk of bias in at least one, and usually across multiple, domains of the Cochrane Risk of Bias Tool. Specifically, trials were often at risk of selection bias (from lack of allocation concealment), detection bias (from lack of assessor blinding) and attrition bias (from incomplete outcome data)."

Willems et al. (2017) discuss the reasons for not using RCTs: „Furthermore, the RCT is the gold standard to evaluate lifestyle change interventions, but an RCT design was not often used in the included interventions. This could partly be explained by perceptions about the ethical issues surrounding the inclusion of people with ID in lifestyle change research. For example, the conflict between one's own autonomy to participate and the dependence on family and staff for participation. Also, previous research shows high drop-out rates and large amount of incomplete data in lifestyle change RCTs for people with ID, which may limit the generalizability of the results. …[Reasons] for greater use of other design studies, that can be implemented more easily, are less expensive and fit the ethical issues experienced in research for people with ID. However, people with ID are entitled to the same level of evidence-based health care as all citizens and the RCTs included in this review suggest that it is feasible to use this design to test the effectiveness of interventions, considering the mentioned difficulties."

Overview of Behaviour Change Techniques (BCTs) and theoretical frameworks

Harris et al. (2018) name the following Behaviour Change Techniques (BCTs):

Prompt practises, provide instruction on how to perform the behaviour, barrier identification/problem solving, action planning, prompt self-monitoring of behaviour, model / demonstrate the behaviour, plan social support / social change, and stress management / emotional control training.

Willems et al. (2017) count the frequency of used BCTs in their included studies (see figure 3 & 4).

Figures 3 & 4: Frequency of used BCTs (Willems et al. (2017)

BCT	Frequency	BCT	Frequency
Provide information on consequences of behaviour in general	27	General communication skills training	5
Plan social support/social change	26	Prompt review of outcome goals	4
Provide instruction on how to perform the behaviour	23	Teach to use prompts/cues	4
Goal setting (behaviour)	19	Facilitate social comparison	4
Prompt practice	17	Stress management/emotional control training	4
Barrier identification/problem solving	15	Use of follow-up prompts	3
Prompt self-monitoring of behaviour	14	Prompt identification as role model/position advocate	3
Action planning	13	Prompting generalisation of a target behaviour	2
Model/demonstrate the behaviour	13	Provide information about others' approval	1
Provide feedback on performance	11	Shaping	1
Provide information on where and when to perform behaviour	10	Stimulate anticipation of future rewards	1
Provide rewards contingent on successful behaviour	9	Provide information on consequences of behaviour to the individual	0

Set graded tasks	9	Provide normative information about others' behaviour	0
Environmental restructuring	8	Agree behavioural contract	0
Prompt rewards contingent on effort or progress towards behaviour	7	Prompt anticipated regret	0
Prompt self-monitoring of behavioural outcome	7	Fear arousal	0
Relapse prevention/coping planning	8	Prompt self-talk	0
Prompt review of behavioural goals	6	Prompt use of imagery	0
Goal setting (outcome)	5	Motivational interviewing	0
Prompting focus on past success	5	Time management	0

The following theoretical frameworks were mentioned as basis for the intervention:

- Social cognitive theory,
- Transtheoretical model,
- Theory of planned behaviour,
- Behaviour change techniques,

- Dynamic systems theory,
- Bronfenbrenner ecological theory of human development.

However, in general, a lack of theoretical frameworks is stated:

Hassan et al. (2019): „An additional limitation is that not all included trials were based on a theoretical framework, which is considered an important prerequisite for designing an effective physical activity intervention".

Williams et al. (2017): „Another similarity in the three study categories was the lack of a theoretical framework to inform the design of the intervention (n=31). … Although a theoretical base is important for interventions in order to be effective and for understanding of the results, a majority of the included studies did not use any kind of theoretical framework. In addition, the BCTs were mostly used in an implicit way, not referring to any theoretical base nor describing the BCT explicitly."

Aspects to pay attention to:

- Differences between people with intellectual disability in general and people with Down Syndrom (Barto & Klein 2011): "We believed this because of the greater quantity of research being published with adults with DS[8] compared with adults with intellectual disability not related to Down Syndrome. Generalizability of the following results to all individuals with intellectual disability should be done with some caution as the majority of participants had Down Syndrom as their origin of intellectual disability". Furthermore, Hassan et al. (2019) stated: "However, while the intervention has shown to be beneficial for young adults with Down Syndrome, additional evaluation is required to confirm if this intervention is effective in different populations with ID."
- Looking at the target group, it becomes obvious that a lot of studies include people with mild and moderate intellectual disabilites and only a few studies examine individuals with severe disabilites. Whether people with Down syndrom are included or not is not always mentioned.
- Age group: "The large age range within the other five studies was notable, and it was not evident from the intervention descriptions if activities were tailored to demographic sub-groups i.e. young adults versus those in middle or late adulthood" (Temple et al.

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[8] DS = Down Syndrom

2017). For example, in the review of Hassan et al. (2019) age of participants varied from 9 months to 83 years.

- Setting: A lot of studies aim at enhancing general participation in physical activity at work, but only a few at home.

- Compliance with the recommendations of the American College of Sports medicine (similar to the recommendation of the WHO): "Only one study in this review achieved the current physical recommondations (150 min of moderate intensity physical activity per week" (Harris et al. 2018).

- Strategies to promotephysical activity: "All studies used face-to-face delivery, except the physical activity intervention of Thomas & Kerr (2011), which was delivered by log-books. These log-books contained information about exercise and helped clients to set personal goals."(Willems et al. 2017) (the log-book was requested without success by NHS Wales via Email in 2019.)

Recommendations / aspects to promote physical activitiy

Booker et al. (2014) describe in common: „Our findings suggest that interventions have had some success in using goal setting strategies, health education focusing on the benefits of PA[9] in a group and individualised format, incorporating PA into the intervention and using group and individual delivery modalities." More specific recommendations from the reviews are listed below:

- Individuality and target needs of users: „When selecting the type of physical activity, thought should be given to the benefit and feasibility of each type of activity … it is important to adapt any intervention to fit the unique physical or cognitive challenges that an individual with intellectual disability presents has." (Bartlo & Klein 2011); „lifestyle change interventions adapted to people with ID to avoid dropout and further improve effectiveness" (Williams et al. 2018).

- Setting and locations: The location is important due to transportation limitations (Bartlo & Klein 2011). „The evidence to date demonstrates that a targeted intervention in the workplace can improve physical activity levels in that discrete context, but to achieve a more pervasive increase in physical activity among adults with intellectual disabilities a 'multipronged' and sustained approach is needed" (Temple et al. 2017).

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[9] PA = physical activity

- Cost of equipment and training of staff: Low cost will be easier to maintain for the longterm (Bartlo & Klein 2011). „Other benefits to a progressive resistance training programme include being simple to perform and relatively simple to resource (improving applicability to the intended population). However, while the intervention has shown to be beneficial for young adults with Down syndrome, additional evaluation is required to confirm if this intervention is effective in different populations with ID." (Hassan et al. 2019).

- Theory framework: „Our findings suggest that the field of lifestyle change for people with ID lacks theory-driven interventions. Although the inclusion of BCTs can contribute to the quality and effectiveness of lifestyle change interventions, researchers should strive to include a detailed intervention description and use rigorous research methodologies." (Willems et al. 2017)

Regarding the theoretical framework two authors mention the International Classification of Functioning, Disability and Health (ICF-model):

- Williams et al. (2018): "However, outcome measures from the ICF categories „environmental factors" and „participation" were often neglected and personal outcome measures were mostly used by a single study. This is surprising, because previous research found that environmental barriers, support from others and personal motivation are relevant to healthy lifestyles for people with intellectual disabilities."

- (Booker et al. 2014): „Interventions should be guided by the theoretical principles asserted by the ICF and should clearly articulate assumptions about where and how interventions are directed. For example, the ICF requires statements about whether interventions are targeted to individual behaviours (e.g., reducing the amount of time spent sitting) or structural factors (e.g., safer environments in which to exercise). Importantly, the ICF requires separation of impairment from disability, in recognition that structural barriers may disable those with cognitive or physical impairments. This is an empowering approach that places onus of responsibility on researchers and other health professionals to amend and adjust physical activity interventions to suit the lives of those with intellectual disability, rather than requiring individuals to fit into programs that might not be tailored to them."

There are hints on the importance of caregivers, daily routine and sustainability:

- „Activity programs by health care professionals and an activity program that can be run by day habilitation staff is more likely to be sustainable" (Bartlo & Klein 2011).

- Hassan et al. (2019): „The involvement of a caregiver as part of the intervention is likely to have been an important contribution to its effectiveness, as caregivers play a key role in encouraging physical activity and can assist in reducing the complexity of a multicomponent intervention. Further, adaptability of a programme to the routines of carers and residents was also favourable as it made the programme easier to implement and supported changes to physical activity. The features of this intervention were advantageous, as, first, the programme used staff members from the day activity centres to conduct the programme at the same facility, so the participants were familiar with the setting and the individuals implementing the intervention. Second, the programme was adapted to the needs of the participants, which helped to incorporate physical activity into their daily routine. This programme highlights the importance of designing interventions that use established facilitators to physical activity; these include support from others, familiarity and routine. It is possible that a lack of motivation (either intrinsic or extrinsic) may have influenced the outcomes of the intervention and participants' intentions to continue performing physical activity in the long term. The use of a mentor, however, has the ability to overcome these barriers and improve physical activity by supporting the individual."

- Hassan et al. (2019): „These findings suggest that a key benefit of the training programme is that it assists people in establishing a routine that involves daily physical activity while also preventing overall physical activity levels from declining over time. … However, while the intervention has shown to be beneficial for young adults with Down syndrome, additional evaluation is required to confirm if this intervention is effective in different populations with ID."

There are also hints on long-term courses and organizational change:

- „Furthermore, a need exists for studies that examine not only the impact of short term health promotion interventions, but also examine the environmental supports and organizational changes that can help sustain these interventions. These approaches could include training of health professionals, administrators, and direct support professionals in community based programs with the aim of changing the culture of agencies serving adults with developmental disabilities." (Heller & Sorensen 2013).

- „It seems clear that programs of a relatively short duration (i.e. 8-12 sessions) targeting a single context are insufficient to produce substantive changes in physical activity behaviour among adults with intellectual disabilities. What is necessary to increase physical activity and subsequently improve weight status remains unclear. Thus, from this review, we recommend that programs designed to increase physical activity among adults with intellectual disabilities simultaneously target the individual with intellectual disabilities as well as their proximal environment (e.g. caregivers) over a sustained period of time." (Temple et al. 2017).

At last, the specific social and cultural context is named as an important but neglected factor:

- „This might indicate that lifestyle change is dependent on the specific social and cultural context, and therefore research in this field might need to be tailored to the specific situation and context of the people with ID. However, the majority of included studies do not properly describe context related characteristics" (Willems et al. 2017)

6.4 Studies

Article overview

In general, 20 studies including 12 interventions plus 1 intervention that has been enhanced from the original are found. The interventions are very different (see for a short overview table 4, for a more detailed overview see attachment 3). Therefore, the components of the interventions are categorized and described / compared below.

Table 4: Overview of interventions

Name of intervention	Aim	Authors
Step to your health	The program was planned to emphasize the benefits of weight loss, exercise, nutritional choices (avoiding fatty foods and simple carbohydrates), and stress reduction.	Ewing et al. 2004, Mann et al. 2006 & McDermott et al. 2012
No name	Promotion of physical activity in older people with intellectual disabilities.	Podgorski et al. 2004
Healthy Lifestyle Chance Program (HLCP)	The HLCP intervention was designed and conducted with a participatory approach to promote physical activity.	Bazzano et al. 2009
Stockholm intervention	This complex health promotion intervention aimed at strengthening knowledge and skills among participants and staff, as well as building a supportive environment.	Elinder et al. 2010, Sundblom et al. 2014, Bergström et al. 2013 &

		Bergström et al. 2014
Take 5	Take 5 is an indvidual intervention involving family or paid carers to support participants, where appropiate. It took place in each individual's home environment.	Melville et al. 2011 & Harris et al. 2017
Physical Activity Knowledge and Skills (PHPAKS) curriculum	Goals of this curriculum are to increase the PA knowledge and skills of adults with ID by using multimedia educational methods within a theory- and literature-based design.	Bodde et al. 2012
	Complemented by an exercise program and staff training	Chow et al. 2016
No name	Weekly physical activity will be supervised by disability staff, who will be encouraged to follow an activity program set out by the university exercise specialist compared to an excercise program.	Lante et al. 2014
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	Two education programs (1 for family / care givers and 1 for people with intellectual disability) regarding the curriculum named on the left side (the current exercise curriculum is described below in chapter d) curriculum).	Yilmaz et al. 2014
Walk Well	Walk Well is an individual behaviour change intervention designed to support participants to make sustained changes in walking, increase overall physical activity levels and reduce sedentary behaviours.	Melville et al. 2015 & Matthews et al. 2016
Technology physical activity	Physically active sessions that incorporate two technology enhanced modalities -- Sony Play Stations's DDR[R] (dance pad) and Nintendo's Wii[TM] Sports (bowling, tennis, and boxing).	Coyle et al. 2016
No name	Multimodal intervention consisting of an one hour session of physical activity where the therapist provided educational advice to people with an intellectual disability to carry out more physical activity and activity sessions to improve physical activity.	Pérez-Cruzado and Cuesta Vargas 2016
Menu-choice	It assists staff in including physical activity goals within the group home schedule. The staff and residents work together to develop weekly goals for residents activity.	Dixon-Ibarra et al. 2017

Setting and Country

Included studies are mainly from Western Countries:

- USA (8 studies with following intervention - Steps to Your Health curriculum, Podgorski et al. 2004, Physical Activity Knowledge and Skills (PHPAKS) curriculum, Technology physical activity, menu-choice),

- Sweden (4 studies from the Stockholm intervention),

- Scotland (4 studies, two each for Take 5 and Walk Well programme),

- Hong Kong (1 – enhancement of Physical Activity Knowledge and Skills (PHPAKS) curriculum),

- Australia (Lante et al. 2014),

- Turkey (1 - Nutritional and Activity Education for people with intellectual disability,
- Spain (1 - Pérez-Cruzado and Cuesta Vargas 2016).

Most of the studies take place in group homes. Table 5 also gives an overview about the less frequently addressed settings:

Table 5: Overview of settings

Setting (as mentioned from author)	Name of intervention
Group home (5 studies)	Menu-choice, Technology physical activity, enhancement of Physical Activity Knowledge and Skills (PHPAKS) curriculum, Stockholm intervention, HLCP intervention
Occupational centre	Pérez-Cruzado and Cuesta Vargas (2016)
Day centres for adults with intellectual disabilities	Walk Well
Training centres for people with intellectual disabilities	Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities
Partner organization	Lante et al. (2014)
Disability Service agencies	Physical Activity Knowledge and Skills (PHPAKS) curriculum
Home environment or convenient location	Take 5
Day habilitation center serving older adults with ID	Podgorski et al. (2004)
Adults who were receiving some service (residential, employment, service coordination) through a network of local disability providers	Steps to Your Health curriculum

Development (basis) and theoretical framework

Table 6: Overview of Developmental basis of the interventions

Name of intervention	Development (basis)
Step to your health	Because there was no available curriculum that covered the desired breadth of topics, the preventive medicine physician wrote the Health Education Learning Program (HELP) manual (Ewing et al. 2004). After the completion of the HELP study the principal investigator collaborated with the author of HELP to develop the STYH curriculum, which is a modification of HELP that incorporates the concrete kinesthetic learning style of adults with ID.
Podgorski et al. 2004	Developed on the basis of American College of Sports Medicine's (1995) standards for group exercise classes.
Healthy Lifestyle Chance Program (HLCP)	The HLCP intervention was designed by „the team" (participatory approach). A project oversight team composed of individuals with intellectual/developmental disabilities, parents of individuals with developmental disabilities, staff, academic researchers, and community-based professionals with extensive experience working with intellectual/developmental disabilities, including a behavioral psychologist, a dietician, fitness instructors, nurses, physicians, a physical therapist, an occupational therapist, a pharmacist, and public health professionals. This team met weekly to decide on all aspects of the program, including planning, curriculurn development, implementation, evaluation.

Stockholm intervention	New developed material with ten themes for use by the staff.
Take 5	Take 5 is based on a weight-loss intervention programme used in Scotland of NHS. It was adapted for people with intellectual disabilities by a multidisciplinary group of clinical academics and health professionals.
Physical Activity Knowledge and Skills (PHPAKS) curriculum	This curriculum was developed using a multistep process of formative implementation and process evaluation (in 4 steps – see below).
Lante et al. 2014	Not mentioned
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	An existing curriculum was used.
Walk Well	Originally, Walk Well was a parent walking programme shown to be effective in studies involving adults, older adults (over 65 years) and as part of a multi-component weight loss programme for men at high risk of cardiovascular disease.
Technology physical activity	The effectiveness of technology is compared and evaluated.
Pérez-Cruzado and Cuesta Vargas 2016	Not mentioned
menu-choice	Program development was derived from an evidence-based nutrition health promotion program for the group home setting.

Bodde et al. (2012) describe the development of an intervention in four steps (see figure 5):

Figure 5: Developmental process of a health education program for PWID (Bodde et al. 2012)
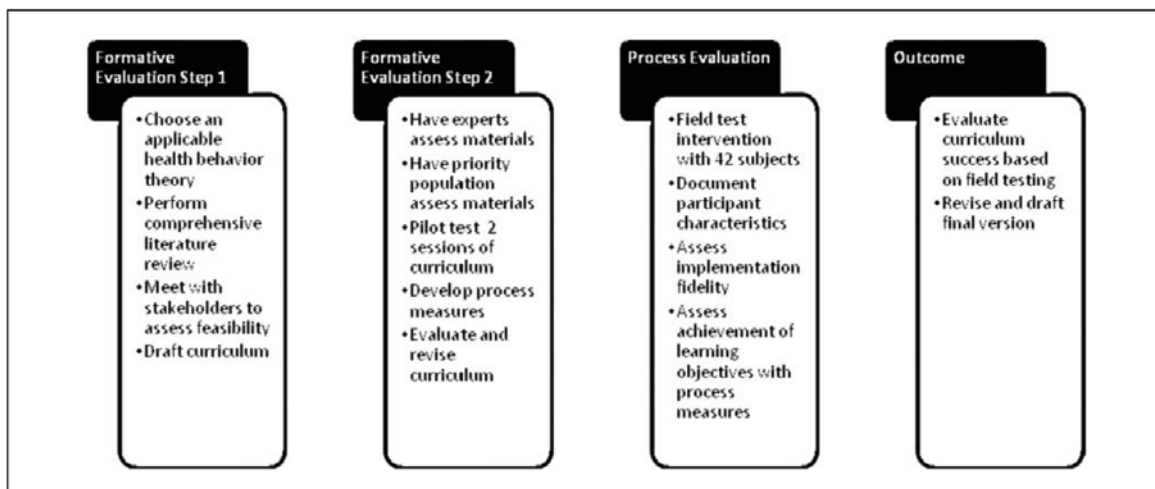
Menu Choice (Dixon et al. 2017) describes the performance of process evaluation:

"Operational guidelines were incorporated by applying theory in the design and implementation phases of the program, by conducting a process evaluation, and by selecting appropriate outcome measures for people with ID[10]. Participation guidelines included stakeholder involvement in development and implementation of the program, considering the values of targeted group by developing the program based on feedback from community stakeholders and providing ample opportunities for personal choice within program materials."

Melville et al. 2015 (Walk Well programme) state: "Therefore, it could be that the behaviour change techniques that contributed to the effectiveness of the parent walking programme are too complex and abstract for most adults with intellectual disabilities. So, those techniques and theoretical foundation must be tailored to the target group." The most mentioned theory for interventions is the social cognitive theory (4 times). But there are other theories for interventions and some named more than one theoretical framework (like Take 5):

Table 7: Overview of theoretical frameworks

Theoretical framework	Name of intervention
Social cognitive theory	Step to your health, Stockholm intervention, Enhancement of Physical Activity Knowledge and Skills (PHPAKS) curriculum, Walk Well
Social Learning Theory	Nutritional and Activity Education for people with intellectual disability
American College of Sports Medicine	Podgorski et al. 2004
Conceptual model of the Healthy Lifestyle Chance Program (HLCP)	Healthy Lifestyle Chance Program (HLCP) – see figure 6 below
Goalsetting	Take 5, menu-choice
Self-monitoring,review of goals and feedback Specific, Measurable, Relevant, and Time-specific (SMART) goals were set relevant to individual dietary habits and physical activity levels.	Take 5
Ajzen's theory of planned behavior	Physical Activity Knowledge and Skills (PHPAKS) curriculum
Goal setting theory & diffusion theory	Menu-choice (goal setting theory (achievable goals with small manageable increases, inclusion of residents in the goal setting process, staff involvement), diffusion theory (different phases in which the adoption of an innovation occurs starting from group home agency managers and program coordinators to staff and residents to change the social system to acceptance of the innovation))
Transtheoretical model of behaviour change	Walk Well

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[10] ID = Intellectual disability

Not mentioned	Lante et al. 2014, Technology physical activity, Pérez-Cruzado and Cuesta Vargas 2016

Bazzano et al. (2009 - HLCP intervention) and Chow et al. (2016 - Physical Activity Knowledge and Skills (PHPAKS) curriculum) explain the construct of social cognitive theory (SCT) used for their intervention:

Bazzano et al. (2009): „The HLCP conceptual model was based on Bandura's social cognitive theory of health behavior change."

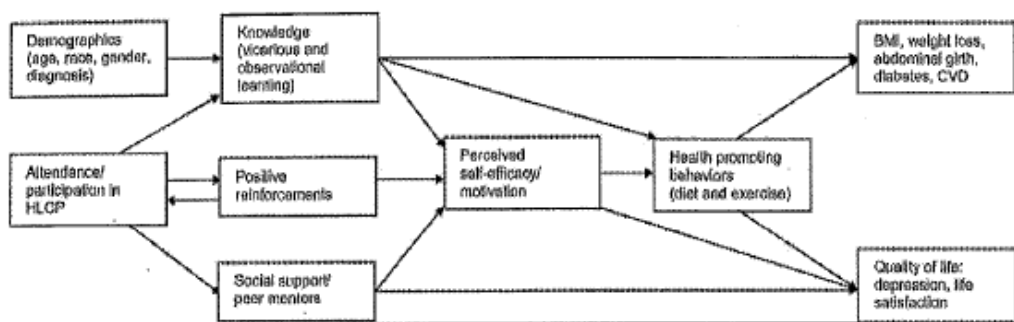Figure 6 Conceptual model of the HLCP (Bazzano et al. 2009).

Figure 7: Targeted constructs in the SCT and the intervention components (Chow et al. 2016)

Target construct according to SCT	Change objectives	Relevant behavior change components
Self-efficacy	Adults with ID think they are able to perform PA	• Setting progressive goals in exercise program • Providing model demonstration during exercise program
Attitude	Adults with ID enjoy participating in PA	• Selecting exercise types according to the preference of the participants
Behavioral reward	Adults with ID feel stimulated and supported by others to perform PA	• Prompt giving of rewards and praise for any attempt at performing PA during exercise program • Presenting of certificate to participants who attended at least 80% of the exercise program • Providing feedback on participants' progress during the education program
Social support	Adults with ID feel safe and comfortable to perform PA	• Providing adequate knowledge (e.g., safety, how to seek help from others) through the education program • Strengthening the knowledge and skills of staff at the residential group homes through staff training

Implementation – barriers and facilitators

Implementation is a crucial stage for an intervention. Some authors describe the implementation process as well as emerging barriers and facilitators.

Elinder et al. (2010, Stockhom intervention) evaluated barriers and facilitators related to the process. They performed an explorative qualitative study. "Interviews are often used when the aim is to gain a deep understanding of a phenomenon where not much is previously known, whereas observations are suitable to use when the aim is to explore what actually happens

during the session."Bergström et al. (2014, Stockhom intervention) as well as Sundblom et al. (2014, Stockhom intervention) show which aspects are crucial for implementation:

Figure 8: Barriers and facilitators in the implementation process (Bergström et al. 2014)

Theme	Creating an individualized supportive context			
Main categories	Individual characteristics	Pedagogical strategies	Interaction within the course	Structures
Sub-categories	Physical function	Trust and security	Participation	Planning and organizing
	Cognitive function	Strategies for various senses	Communication	Physical environment
	Motivation	Support and adaptation	Staff involvement	Routines for collaboration
	Self-efficacy			Support for course leaders

Figure 9: Important aspects for an implementation process (Sundblom et al. 2014)

Supporting motivation for change			
Intervention characteristics	*Individual commitment*	*Organisational capacity*	*Societal influences*
Compatibility and perceived needs	Competence and interest among staff	Work routines	Local policies and sanctions
A flexible and participatory approach	Interest among residents	Financial and staffing resources	Accessibility to a healthy environment
External input to staff and residents Support and preparation	Attitude of trustees and relatives	Work climate and leadership	Trends and media messages

Dixon et al. (2017) present key concepts of the Menu-Choice Program, which are important for a successful implementation:

- "Relative advantage was decribed during training to express that the program advantages outweigh the negative outcomes of physical inactivity for the residents
- Compatibility was an integral part of program design to make the program consistent with the practices and culture of the group homes system (e.g. using goals and check lists)
- Communicability was included in the design and implementation as we provided an easy step explanation of the program for staff to follow.
- Simplicity was a key elementwhen designing the program for ensuring it to be easy to follow and implement. A one-page step by step guide was created for ease of access.
- Trailability was the main purpose of the feasibility study where the group home had the opportunity to test the program prior to adopting it in their agency.
- Time to implement the program' was addressed by creating a program that would take minimal time to organize and implement."

Bodde et al. (2012 - Physical Activity Knowledge and Skills (PHPAKS) curriculum) point out the challenges of volitional control of people with ID and the influence for an intervention of promoting physical activity: „Many adults with ID do not have complete volitional control over their activity choices because of staffing constraints and transportation limitations. Therefore, it cannot be assumed that their intention to perform a behavior will directly lead to a behavior. For this reason, lessons were developed that emphasize activities adults with ID may actually have control over, such as activities that can be done at home using household items or while watching TV. Activities without the required supervision or transportation of a staff or family member were also included."

<u>Types of physical activity and exercise</u>

Table 8: Overview of types of physical activity and exercises and interventions

Physical activity	Name of intervention
Daily life activities (e.g. walking, doing activities while watching tv)	HLCP intervention, Take 5, Physical Activity Knowledge and Skills (PHPAKS) curriculum, Lante et al. (2014), Pérez-Cruzado and Cuesta Vargas 2016, Steps to your health, Walk Well programme,
Exercises (but with focus on integrating activities in daily life),	Step to your health (mentioned in lessons), Podgorski et al. (2014), HLCP intervention, Enhancement of Physical Activity Knowledge and Skills (PHPAKS) curriculum, Lante et al. (2014),
Playing Nintendo Wii[TM] Sports oder Sony Play Station's Dance Dance Revolution	Technology physical activity
Only physical activity mentioned, no differentiation	Stockholm intervention, menu choice
Objective of understanding lifestyle, promoting health, giving motivation to promote health lifestyle behaviour, and increasing the performance of exercise.	Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities

The main activities are daily life activities and exercises with education lessons, explaining how to integrate it in daily life. Sometimes it is not clear what is actually meant by the term physical activity, because it is not further differentiated (Stockholm intervention). This was already a challengein the process of deciding forin- or exclusion of studies.

<u>Are competencies for physical activity of users* analyzed and if so, how?</u>

Table 9: Development basis for interventions

Name of intervention	Development (basis)
Step to your health	The completion of a written knowledge test, a fruit and vegetable assessment, and an exercise test.
Podgorski et al. 2004	A fitness trainer spent 3 weeks at the site prior to the baseline evaluation getting to know the individuals, their physical limitations, their styles of communication, and their comfort levels with new things, new people, and other consumers.

Healthy Lifestyle Chance Program (HLCP)	Health assessment: a pertinent history, physical exam, and medical records review was performed by nurses and physicians. Referrals were made for needed primary care, preventive screenings, diagnostic tests, and specialty care.
	Preventive health screening recommendations were based on the U.S. Preventive Services Task Force Guide to Clinical Preventive Services, and recommendations for acute problems were based on physician judgment. Nurses followed up on all referrals to ensure that appointments were made and kept.
Lante et al. 2014	Completion of a Physical Activity Readiness Questionnaire (PAR-Q) and where concerns are identified by the PAR-Q, medical clearance will need to be obtained in order to participate in the study.
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	A medical report stating that they could do exercise.
Technology physical activity	Medical Clearance: they must have, within the past 3 months, a signed physican permission form to be allowed to take part
Menu-choice	Each resident needed to complete a PAR-Q to determine physical activity readiness. The special activity needs sheet (SAN) was a one page communication aid with the goal of a safe and pleasant physical activity experience for the residents.

Duration of the interventions

The length of interventions was very different, ranging from 8 weeks to 12 – 15 months (Stockholm intervention). Most of theinterventions did not last longer than 12 weeks (3 months), except Menu-choice (16 weeks), HLCP intervention (7 months), and Take 5 (12 months).

Needs of participants / participative developmental approach

Four studies mentioned that they explored the needs of participants, by interviewing either staff/stakeholders (n=2) or people with ID themselves (n=2).

- Stockholm intervention (Elinder et al. 2010): „The themes were developed in discussions with managers of community residences and on the basis of their knowledge of the needs of the target group."

- Menu choice (Dixon-Ibarra et al. 2017): „health promotion program guideline first step: identifying needs of stakehoders in the group home-setting." – „Participation guidelines included stakeholder involvement in development and implementation of the program, considering the values of targeted group by developing the program based on feedback from community stakeholders and providing ample opportunities for personal choice within program materials" And the program itself: „it assists staff in including physical

activity goals within the group home schedule. The staff and residents work together to develop weekly goals for residents activity."

- Physical Activity Knowledge and Skills (PHPAKS) curriculum (Bodde et al. 2012): „A unique aspect of the program was the inclusion of adults with ID into the curriculum development and analysis process. A group of four adults with ID met twice and pilot tested two lessons of the program. In addition, they were asked to comment on the readability of the curriculum and the visual materials. A second draft of the curriculum was subsequently developed using the feedback from the reviewers and the pilot tests with four participants. In addition, process measures were created that matched each learning objective of the curriculum."

- HLCP intervention (Bazzano et al. 2009): „community based participatory research (CBPR) principles and methods are conducted in partnership with community members to produce more effective and sustainable interventions that address the community's needs and desires. A project oversight team composed of individuals with developmental disabilities, parents of individuals with developmental disabilities, staff, academic researchers, and community-based professionals with extensive experience working with developmental disabilities, including a behavioral psychologist, a dietician, fitness instructors, nurses, physicians, a physical therapist, an occupational therapist, a pharmacist, and public health professionals. This team met weekly to decide on all aspects of the program, including planning, curriculum development, implementation, evaluation, and dissemination. Academic researchers acted primarily as consultants providing information and facilitating discussion. Individuals with developmental disabilities also completed a series of leadership and health trainings to become peer mentors who collaborated to lead program activities."

Involving organization / management

Menu choice (Dixon-Ibarra et al. 2017): „agency managers and program coordinator attended a three hour training session to get familiar with program and materials".

Stockholm intervention (Elinder et al. 2010): „Health ambassadors receive coaching by the research team and provide support to other staff members. - Network meetings are arranged four times during the intervention. The first meeting is an introductory meeting and following meetings focus on themes chosen by the ambassadors. - study circle [to discuss the process of the project) for staff are offered included in staff meetings."

One study suggests to include physical activities in organizational policy:

Stockhom intervention (Sundblom et al. 2014): „However, this study has shown that there is room for further improvement of implementation strategies regarding the preparation phase and policy development to support health promotion."

Health Education (for people with ID and staff)

Due to the different aims and approaches to intervention development, the concepts of health edcuation vary a lot. Because we are interested in getting an idea about the type of existing interventions, we just give an overview and do not provide any detailed comparisons of the interventions. Table 10: Overview Health Education for people with intellectual disabilites

Name of intervention	Health Education for people with intellectual disabilities
Step to your health	The STYH intervention consisted of eight sessions, each focused on a target issue, and class participation included discussion, practice time, group activities, and healthy snacks for the participants. Transportation was provided and sessions were held in a room provided by the disability service agency in the local area where the participants lived. The beginning of each session was used to summarize and discuss the previous lesson, answer questions, and bring up successes and problems. The sessions were organized around the following topics during the eight weeks: • Lesson 1 Nutrition I (emphasis on fruits and vegetables) • Lesson 2 Nutrition II (emphasis on whole grains and portion size) • Lesson 3 Exercise • Lesson 4 Stress management • Lesson 5 Changing your way of thinking • Lesson 6 Communication styles (asserting preferences) • Lesson 7 Complications of obesity • Lesson 8 Behaviour management The vocabulary and the learning materials were concrete, and every lesson was infused with examples and exercises. The spacing of the sessions, at one-week intervals, was the desired frequency stated by participants who assisted with the design of the intervention.
Healthy Lifestyle Chance Program (HLCP)	Eucation and exercise sessions: Each class included 50 minutes of interactive health education, a 10-minute healthy snack break, and 1 hour of supervised physical activity. Provider led interactive activities that supplemented didactic material. Based on client feedback from the focus groups, core aspects of the final program included: (1) client peer mentoring; (2) interactive health education; (3) supervised physical activity; (4) behavioral modification; (5) one-on-one health management education and advocacy; (6) clinical support; and (7) a supportive social network.
Stockholm intervention	Health ambassadors get in contact with residents and plan physical activity.
Take 5	Each session lasted 40-60 min. TAKE 5 compromised nine sessions and followed a structured format, with specific defined content to be covered for each session. The intervention was delivered by a dietitian and a health professional, trained for the purpose of this study, delivered both programmes. Behavioural methods are incorporated in every session (goal setting and self-monitoring are central and were added by methods to maintain participants and carer motivation e.g. avoiding certain keywords, stimulus control and problem solving. Focus on diet, but contains physical activity as an important factor of this intervention. Sports and ecercise information was given to each participant and carer on local leisure facilities and clubs with accessible sports and exercise groups/classes.
Physical Activity Knowledge and Skills	To increase PA knowledge, skills, and actual control, each lesson was designed to address one of three behavioral constructs of the theory of planned behavior. For example, perceived behavioral control was incorporated into four of the eight lessons. Each of the pictures used in these pictorial instructions showed a person with ID demonstrating the skill. Second, the curriculum included short interactive video clips designed to demonstrate PA concepts. The

(PHPAKS) curriculum	video clips were integrated into a split-screen video demonstration for the instructor to use during the class. For example, the video for lesson 1 showed a participant playing basketball and a participant sitting and listening to music. After viewing the splitscreen display, participants were to be asked in class to correctly identify which video demonstrates PA. Third, each week, every participant had a photo taken of them demonstrating the skill they acquired in class. Participants were asked to save each picture that they would keep to serve as a lesson content memory tool (e.g., a picture taken of them properly using their new pedometer). Two sessions of the curriculum were designed to address the physical, mental, and emotional benefits of PA. Several activities were included in the current curriculum to help increase social support skills for PA participation. Multiple role-playing activities were added: for example, participants practiced inviting a friend to go for a walk with them. They were also made aware of community opportunities for team sports such as the locally available Special Olympics teams in which to participate at no cost. As such, one lesson would equip people with ID with the necessary knowledge and skills to safely participate in PA and address the concerns of hydration, pain, and weather appropriate dress.
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	See chapter d) curriculum
Walk Well	Walk Well involved three face-to-face meetings over a 12 week period between participants, carers where appropriate, and a walking advisor. Prior to the start of the intervention the walking advisor received training on communicating with adults with intellectual disabilities, motivational interviewing and delivering physical activity consultations. The physical activity consultation had a semi-structured format and a person centred approach to ensure it was individualised to the needs of the participant with intellectual disabilities.
Pérez-Cruzado and Cuesta Vargas 2016	A one-hour session of physical activity where the therapist provided educational advice to people with an intellectual disability to carry out more physical activity. The tips given in the educational advice are: Tips for going around town: • Walk to the shops, post office, school, neighbours. • Park in the furthest space in the car park. • Walk around the waiting room, airport or anywhere where you have to wait. • Practise 'active shopping' by first walking around the bleck and looking before you start buying. Tips for home: • Hide your remote and change channels as you used to. • Put on some lively music while you are doing housework. • Get up and walk around during television commercials. • Walk the dog. Tips for family and friends: • Walk, run and play actively with the kids. • Go hiking with family and friends, so you are enjoying social time while exercising. • Make time for a regular 'family walk'. • Plan active holidays and getaways.
Menu-choice	It assists staff in including physical activity goals within the group home schedule. The staff and residents work together to develop weekly goals for residents' activity. The program includes a resource binder, weekly scheduling sheets, visual calender and post it activity pictures for the residents. The resource binder includes resources for staff to learn about physical activity, activity examples, information about goal setting, and guidelines for specific disabilities within the group home setting. The calender allows residents to post pictures of their activity across the weak and check off when they complete their goals. Contents of intervention: 1 Step by step guide to menu-choice

	2 Physical activity education section
	3 Residents special activity needs sheet
	4 Goal setting education section
	5 Resident choice activities
	6 Menu-Choice activity modules
	7 Menu-Choice activity progressions
	8 Weekly activity schedule (goal setting sheet)
	9 Residents visual activity calendar
	10 Goal evaluation sheets
	11 Finding motivation activities
	12 Staff and resident activity champions

Health education for staff/managers:

Steps to your health (Mann et al. 2006): „staff members employed by community disability service providers, who were given training and technical support for conducting the program by two university professionals."

Stockholm intervention (Elinder et al. 2010): „ The health ambassador receives coaching by the research team on issues regarding diet, physical activity and health and gets the possibility to exchange knowledge and experiences during network meetings with health ambassadors from the other residences. Network meetings are arranged four times during the intervention. … The aim of the study circle is to increase the knowledge and skills of staff in the area of health promotion in order to empower them to improve work routines and the social and physical environment of residents. Normally, staff in community residences meet once every second or fourth week. We decided that these meetings would be a good opportunity for the staff to conduct this study circle using the study material "Fokus Hälsa" (Focus Health)."

Enhancement of Physical Activity Knowledge and Skills (PHPAKS) curriculum (Chow et al. 2016): „The intervention included a staff training component. As social support can be provided by the staff of the group homes, the content of the 2-hour staff training session included increasing cognitive awareness of the importance of providing physical activities to the residents, the use of behavioral change strategies in promoting physically active lifestyles, and the practical skills needed to lead physical exercises."

Nutritional and Activity Education for people with intellectual disability (Yilmaz et al. 2014): they included an education program with four lessons offered to the families/care givers.

Menu Choice (Dixon-Ibarra et al. 2017): „it assists staff in including physical activity goals within the group home schedule. The staff and residents work together to develop weekly goals for residents activity. Agency managers and program coordinator attended a three hour training

session to get familiar with program and materials,- program coordinators trained support staff over a two-week period.“

<u>Providers for people with intellectual disability</u>

Table 11: Overview of providers

Name of intervention	Provider
Step to your health	The classes were taught by staff members employed by community disability service providers, who were given training and technical support for conducting the program by two university professionals.
Podgorski et al. 2004	Fitnesstrainer
Healthy Lifestyle Chance Program (HLCP)	Professionals with expertise in developmental disabilities taught sessions with assistance from peer mentors.
Stockholm intervention	Health education for residents: health educator from "StudieförbundetVuxenskolan" using the educational material "Hälsokörkortet" (Driver's licence for health). Health ambassadors: The health ambassador receives coaching by the research team and provides support to other staff members. Study circle for staff: included in staff meetings.
Take 5	Health professionals who had experience in working with individuals with intellectual disability - a dietitian and a medically qualified sports medicine graduate.
Physical Activity Knowledge and Skills (PHPAKS) curriculum	Instructor followed a script (Enhancement: Exercise program: instructor who has a physical education diploma with sport coaching experience and experience in working with adults with ID). Educational program and staff training: not mentioned (researcher?)
Lante et al. 2014	Intervention group 1: Exercise specialists from the University of Sydney and supervising of physical activity by disabilty staff Intervention group 2: Exercise specialists from the University of Sydney
Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities	Education program from researchers
WalkWell	Walking advisor
Technology physicalactivity	Researcher
Pérez-Cruzado and Cuesta Vargas 2016	Therapist
Menu-choice	- researcher to acency managers and program coordinators - program coordinators to staff - staff work together with residents

Health ambassadors (Stockholm intervention), who are trained staff, and peer mentors (HLCP intervention) can play an important role during interventions - for example, peer mentors modeled effective interactions during a physician visit, and they demonstrated safe cooking techniques or an exercise video created by the peer mentors (Bazzano et al. 2009).

„Individuals with developmental disabilities also completed a series of leadership and health trainings to become peer mentors who collaborated to lead program activities. …

Peer mentors. Eleven adults with developmental disabilities were hired as peer mentors. Clients, client rights advocates, and parents of individuals with developmental disabilities introduced the concept of peer mentors to the team, believing peers were better equipped than professionals to support others who face similar challenges, life experiences, and barriers to health. Peer mentors were recruited through flyers, job advertisements, community presentations, and referrals from WRC[11] case managers and community organizations serving individuals with developmental disabilities. All potential candidates underwent an application process and were interviewed by team members. Peer mentors were selected based on leadership potential and enthusiasm and/ or life experience regarding healthy lifestyles. Peer mentors collaborated on program planning, curriculum revision, and participant recruitment. The HLCP was piloted with the peer mentors, who provided recommendations on logistic issues (when and where to hold classes); educational topics; developmental level; need for repetition and visual tools; sensitivity; potential limitations; and ways to adapt the program for the larger group. Peer mentors suggested the program to be conducted at WRC rather than at other locations in the community because it was familiar, accessible, and centrally located, with a bus stop nearby. Peer mentors received training on health and fitness, leadership, and motivational strategies, so that they could serve as leaders, teachers, and role models for healthy behavior. They made reminder phone calls to participants, led physical activity sessions, prepared healthy snacks, and helped to facilitate review sessions and evaluation assessments.' Peer mentors also presented program results at community meetings and academic conferences alongside researchers" (Bazzano et al. 2009).

Dixon et al. (2017 - Menu Choice) state the following:

-" there was no staff that worked consistently (staff turnover and limited staff)

- policy level was not taken into account

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[11] WRC = Westside Regional Center

- staff and program coordinators, which themselves had high BMI and low activity levels, may not have found value in implemting an activity program (role model)"

Home visits and one-on-one sessions

Step to your health (Mann et al. 2006): „All participants were offered two home visits to establish an individual exercise program (e.g., walk around the neighborhood with the individual to show the recommended pace and distance to walk), develop a dietary plan (e.g., look in the refrigerator and cabinets to assess daily dietary patterns), and make a grocery store visit to identify healthy choices."

Take 5 (Melville et al. 2011): „Take 5 is an indvidual intervention involving family or paid carers to support participants, where appropiate. It took place in each individual's home environment."

Walk Well (Melville et al. 2015): „Walk Well involved three face-to-face meetings over a 12 week period between participants, carers where appropriate, and a walking advisor. Prior to the start of the intervention the walking advisor received training on communicating with adults with intellectual disabilities, motivational interviewing and delivering physical activity consultations. The physical activity consultation had a semi-structured format and a person centred approach to ensure it was individualised to the needs of the participant with intellectual disabilities."

Melville 2011 (Take 5): „An individual intervention was believed to be more likely to be accessible to all adults with ID. … Although the changes in moderate-to-vigorous levels of physical activity were not significant, participants made clinically relevant changes to their levels of sedentary behaviour and light-intensity physical activity."

Melville et al. (2016) comment: "The additional barriers to physical activity experienced by adults with intellectual disabilities mean that decision making and actions are most often expressed in the context of existing personal relationships and the majority of participants in Walk Well were supported by family or paid carers during walking. However, many participants and carers reported difficulties finding time to walk together. … [Therefore there must be a guideline] even when social care support is available, it is often not funded at a level that allows paid carers to support adults with intellectual disabilities to be physically active." They further note: "Additional support from external organisations could reduce the social capital/ networks barriers to adults with intellectual disabilities participating in community activities caused by reductions in social care support. For example, social enterprises, volunteer

organisations and buddy programmes may all have a role to play in supporting adults with intellectual disabilities to be more active."

How is the motivation of the participants discussed?

Podgorski et al. (2004) discuss factors that influence the selection of activities: "Participants were encouraged to try the fitness challenges prior to the baseline assessment. A wide variety of factors influenced the selection of activities within these sessions, including the broad range of cognitive abilities among the participants; fear of the unknown and the challenge of change, safety issues, variability in learning times, medical issues, tolerance for interpersonal contact, communication abilities, ability to be self-directed, and cognitive levels, creation of a perception of "fun" as opposed to "work" or a "test"; space contraints, and cost."

Stockhom intervention (Sundblom et al. 2014): "The overarching theme emerged out of the contents of the main categories. It describes the importance of supporting motivation for change among managers, caregivers and residents when implementing a health intervention in community residences. The intervention needs to be designed to support the participants to find their own motivation to engage in the project, as stated by one of the health managers;

I would say this is the key, I mean to be able to make someone else feel motivated. (Health ambassador in Residence 5)

From the perspectives of managers and health ambassadors, both caregivers and residents have to find their individual motivation to make changes. Furthermore, the support has to be tailored to each residence as well as for each individual, taking their specific needs and preferences into account."

Take 5 intervention includes methods to maintain participant and carer motivation and methods for problem solving.

Walk Well: "Prior to the start of the intervention the walking advisor received training on communicating with adults with intellectual disabilities, motivational interviewing and delivering physical activity consultations. Participants were also motivated to work towards their end of study certificate.'We could see [the step count] and say "Look how many steps you did today". If he got higher the next day he was quite proud of himself.' (Paid carer 1)'He enjoyed the fact that he reached his goal to get the certificate. That's right, he completed something. He always likes to finish things when he starts them. Sometimes in X's life it is difficult for him to complete things.' (Family carer)"

Bazzanno et al. (2009) looks at the needs and by doing this also at motivation: :

"For example, based on insights from team members with developmental disabilities, the program's exercise component was not integrated into existing community health clubs because of concerns that participants would feel awkward or out-of-shape if surrounded by typical Los Angeles health club members."

Pérez-Cruzado and Cuesta Vargas (2016): "The educational intervention included in physical activity is of great importance since it is one of the main components that motivates people with intellectual disabilities to the realisation of physical activity."

And Harris et al. (2017) discuss about staff motivation: "Several explanations were presented for poor engagement by carers, including: low morale and changes in the working environment; the burden of paperwork and other administrative duties for participants; lack of consistency in shift patterns; lack of communication between carers; and being responsible for more than one individual with intellectual disabilities.

How are the interventions evaluated?

The evaluation of the interventions varied a lot due tothe specifics of the interventions, see attachment 3 for more details. In this chapter, we will provide a short overview of interesting approaches and challenges for participants to take part in the evaluation process:

HLCP intervention (Bazzano et al. 2009): "Evaluation. At the request of team members, researchers performed a Iiterature review of published weight loss programs to guide development of outcome measures and program evaluation. The team reviewed all evaluation tools for developmental appropriateness, relevance to research questions, ease of administration, and acceptability to clients. All team members made descisions on outcome measures and tools using a democratic process. Outcomes were assessed at baseline and at 7 months (program completion). In addition to the outcomes described below; health knowledge questionnaires were self-administered with help from peer mentors and project staff, and the Beck Depression Inventory®-II(BDI-II) 23 was administered by mental health professionals. Knowledge questionnaire results are not reported, because peer mentors and support staff mistakenly assisted participants with answers. The results of BDI-II are not reported due to participant difficulty in comprehending and completing·the tool."

Similar problems occurred within the Walk Well programme (Matthews 2016): "Feedback from participants, carers and the study team identified the participant burden of the data collection questionnaires."

Steps to your health (Mann et al. 2006) gives support to participants as follows: "The instructors read the questions to each participant and talked with the individual about the concepts embedded within each question. For example, when the question pertained to exercise frequency, the instructor talked to the participant about days of the week to determine whether the individual understood these concepts. If they did not, the interviewer asked the person who brought the individual (e.g., parents, group home staff) if he or she could answer for them; thus, for some participants, informants were used. In all cases, the informant-reported information was shared with the study participant to assess whether or not he or she agreed."

Podgorski et al. (2004) conducted a one-year-follow-up study. „After 1 year, many of the participants continued to improve in one or more aspects of physical function performance." A follow-up seems to be interesting for an intervention evaluation and meaningful to assess the sustainability of an intervention.

Ethical statements

Sunblom et al. (2014): "Ethical dilemmas and conflicts between providing support and respecting autonomy are well-known challenges in this setting, and also in this study, there was a great need to discuss these issues."

In more detail:

Matthews et al. (2016): „Finally, the complex issue of 'freedom of choice' needs careful consideration for adults with intellectual disabilities. One participant reported feeling 'pestered' or 'nagged' by their day centre staff into joining the study. In line with Good Clinical Practice no individual should feel pressured to participate in research. Autonomy is one of the four cornerstones of good ethical conduct; along with beneficence, non-maleficence and justice. However, exercising autonomy and reaching an informed decision requires deliberation, understanding and decisional balance; cognitive skills that some adults with intellectual disabilities may not have. To make an informed lifestyle choice they need to effectively consider the benefits and risks of positive and negative behaviour [46]. This led to debate by carers on 'freedom of choice' and 'health improvement' i.e. Was encouraging individuals who lacked motivation a bad thing? Or was not encouraging individuals, because they lacked motivation, a bad thing? This uncertainty over 'freedom of choice' was demonstrated in our study where participants, supported by carers, were sometimes entrenched in poor lifestyle behaviours, for example, eating several boxes of chocolates or using a taxi for a distance of 200 m."

Bergström et al. (2014): "The interactional patterns during course sessions indicated dominance from the course leader. This has previously been identified in classroom situations as well as between caregivers and people with intellectual disabilities in regular conversations. Some of the dominance can be explained by the tutorial role of a course leader, but that does not exclude possibilities for interaction-based learning. This was shown by course leader F, who based the educational strategies on the contributions of the participants, which resulted in livelier communication and interaction in these groups than in the other groups. In the smallest and largest groups, interactional difficulties were observed, which can probably be attributed to both group size and pedagogical strategies. However, ideal group size and similar levels of ability in a course must be weighed against the advantage of holding the course in a familiar social context with greater possibilities ofsupport in daily routines.

Realization of activity in everyday life

Bergström et al. (2014 – Stockholm intervention): "The health course offered good opportunities for the participants to increase health literacy in a group activity where they, without the presence of caregivers, got the possibility to practice autonomy. The course focused more on health literacy than on the empowerment process though. *There was a lack of support within the social and physical environment, to adequately support the use of new skills within everyday life.* Challenges that have to be addressed when implementing health education for this target group in the future include improved adaptation to individual characteristics, pedagogical strategies that meet different learning styles and include participation in every part of the process and planning for well-functioning structures. To increase health related behaviours it is important to improve health literacy as well as supporting the empowerment process. This might be achieved by creating an individualized supportive context in collaboration with caregivers and relatives.

6.5 Curriculum

Marks et al. (2010) offer a Health Education Curriculum for Nutrition and Exercise. Although the main focus is on exercise, there are lessons included that are important for our research interest. Next to the exercise and nutrition classes, health education classes are an important aspect of the curriculum. Those classes are intended for 3 days per week for 1 hour over 12 weeks, with a number of 6 – 10 participants. It is also developed for people with severe/profound intellectual disabilities as well as for a variety of physical disabilities. „The lessons consisted of activities helping participants to understand their attitudes toward health, exercise and food, find exercises that they like to do and set goals, gain skills and knowledge

about exercises and healthy eating, support each other during the course of the class; and identify in their community where they could exercise regulary."

„The curriculum is based on Bandura's Social Cognitive Theory and the five stages of change in the Transtheoretical Model of behavior Change: precontemplation [not interested], contemplation [thinking about it], preparation [planning], action [doing], and maintenance [still doing]."

Before starting the programme, the following steps should be considered:

1. Obtain permissions from a health care provider for each participant.
2. Encourage participants to do physical activities throughout the day (daily routines).
3. Make sure that the program is based on sound and tested theory (see above).
4. Teach participants to exercise a minimum of 3 days per week for at least 30 minutes.
5. Keep the program fun and rewarding.
6. Foster fitness among staff and caregivers.

Above that, it is concidered that „maximum individual involvement in the planning and implementation of exercise and nutrition goals" should be reached. Other techniques for the curriculum are:

Problem solving techniques, conflict resolutions, role playing, using open ended questions, giving attention to individual learning styles, field trip activities, incorporating newsletters and evaluating changes in participants.

The curriculum offered instructions for the lesson provider as well as materials for each lesson in easy language and with pictures for following lessons:

Unit 1. Physical Activity and Nutrition: Making Healthy Choices

Lesson 1: What Is Health?
Lesson 2: What Is Physical Activity?
Lesson 3: Things to Do Before We Exercise
Lesson 4: Exercise Is Good
Lesson 5: What Do Different Exercises Do for My Body?
Lesson 6: Good Nutrition
Lesson 7: How Much Energy Does It Take?
Lesson 8: Healthy Choices/Self-Advocacy

Unit 2: Changing Lifestyle: What Are the Things We Do?

Lesson 9: What Do I Think of Me?
Lesson 10: What Is My Heart Rate?
Lesson 11: What Is My Blood Pressure?
Lesson 12: What Exercises Do I Like in My Community?
Lesson 13: What Are Good and Bad Influences?
Lesson 14: Am I Drinking Enough Water?
Lesson 15: What Foods Do I Like to Eat?
Lesson 16: How About My Medications and Exercise?

Unit 3: Making Lifestyle Changes: Setting Goals

Lesson 17: Things to Remember When Exercising
Lesson 18: Community Fitness Center Visit: Using Exercise Machines Safely
Lesson 19: How to Breathe When We Exercise
Lesson 20: Why Do We Clean Equipment?
Lesson 21: Nutrients We Need
Lesson 22: Exercise Plans: Becoming More Active
Lesson 23: Nutrition Plan: Making a Menu

Unit 4: Lifestyle Changes: Doing My Program

Lesson 24: Wants and Needs: Doing Different Exercises in My Community
Lesson 25: What Is Good Pain and Bad Pain?
Lesson 26: How Does Sleep Affect Physical Activity?
Lesson 27: Negotiation and Compromise
Lesson 28: Can I Exercise If I Feel Sick?
Lesson 29: Am I Meeting My Goals?
Lesson 30: Rewarding Myself

Unit 5: New Lifestyle: Keeping My Program Going

Lesson 31: Restructuring My Environment
Lesson 32: Getting Back on Track
Lesson 33: Creating an Exercise Video
Lesson 34: Reviewing Our Goals to Stay Connected
Lesson 35: Putting It All Together
Lesson 36: Finishing Touches on Our Video
Lesson 37: Graduation Party

7) Limitations and strengths of this review

We searched numerous databases for this scoping review, but we had no access to one potentially important databases (Sport-Discus). Furthermore, we did not perform a hand search on important journals (e.g. Journal of Intellectual Disability Research or Journal of Applied Research in Intellectual Disabilities). However, the journals are indexed in Medline and the main articles on the topic should be included. In contrast to us, the included systematic reviews took these data sources into account and we browsed through those references, so that we assume, that no relevant intervention is missing. Our decisions for inclusion and exclusion are very subjective. For example, we included the curriculum by Marks et al. 2010, but did not include studies working with this curriculum, because our main interest was getting an overview about existing types of physical activity interventions and not testing exercise groups. We also did not include the curriculum „Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program", also by Marks et al. (2010), which belong together, but have different appoaches. We included the intervention of Coyle et al. 2016 because of their view on daily life actions with technology but excluded other interventions with technology like XBOX due to their focus on more additionial groups using technology. Podgorski et al (2004) was only included because of the existence of a 1-year-follow up period; long-term measurements are rarely found. However, referring to our research interest, we believe to have found a representative selection of studies for gettings hints on conceptualizing

an intervention for our purpose. The decision for the year selection (20 years range) is based on the assumption, that new research findings take into account the latest trends according to autonomy according UN Disability Rights Convention. We are convinced that we have interventions taken into account according to the latest development in research, health systems and approach to people with intellectual disability.

Because we did not identify (and excluded) articles, which are already included in overviews/systematic reviews, there is a risk of having referred to some studies more than one time (e.g. in review and studies). Nevertheless, this seemed to be eligible because it was our intention to gather information purposeful and build a pool of ideas, rather than analyzing and comparing involved studies. Thus, we also did not describe the outcomes and quality of studies, which seems to be a general problem in research with people with intellectual disabilities (see chapter 6.3). Also, key messages of the findings were not discussed. However, as already mentioned, within this funding period the main focus lies on basic research, development and validation of the intervention. We will concentrate on evaluation processes and challenges in a following research period.

8) Implications for our research project

In this detailed results presentation, we described the execution and findings of a scoping review. We aimed at answering the primary question "What is the state of the art in interventions to promote physical activities addressing daily life situations for people with intellectual disabilities?" For this, we mapped the data for each category, except the curriculum and answered our secondary research questions. Categories were added if we identified them as important for the conceptualization of our intervention. In this chapter, we conclude by briefly summarizing the findings and implications for our research project.

The scoping review describes the current state of the art in interventions to promote physical activity in daily life of people with intellectual disability. It results in a tool box (pool of ideas), that will be a basis for the development of our own intervention. For example, the tool-box contains information about preparing research in this field (e.g. ethic statements), about strategies for educating people with ID and/or staff, but also about strategies for overcoming barriers and facilitating life style change. While writing this detailed results presentation, we are in the process of analyzing the individual movement experiences as well as desires and needs of our study participants via methodological triangulation. The conceptualization of the intervention will finally be based on those results. What may work best will be discussedwith future users (people with intellectual disability) and staff members in a participatory approach.

The developmental processof the intervention, involving the considered findings, will be described in the handbook of the förges-network, which will be published in 2021.

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