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Author manuscript

J Appl Res Intellect Disabil. Author manuscript; available in PMC 2017 July 01.

Published in final edited form as: *J Appl Res Intellect Disabil.* 2016 July ; 29(4): 378–386. doi:10.1111/jar.12205.

## Including youth with intellectual disabilities in health promotion research: development and reliability of a structured interview to assess the correlates of physical activity among youth

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## Abstract

**Background**—The input of youth with intellectual disabilities (ID) in health promotion and health disparities research is essential for understanding their needs and preferences. Regular physical activity (PA) is vital for health and wellbeing but levels are low in youth generally, including those with ID. Understanding the perceptions of and barriers to PA in this population is important for designing effective interventions.

**Materials and Methods**—We developed a structured interview that queried youth with ID and typically developing (TD) youth (ages 13–21 years) about their enjoyment, preferences, and perceived barriers to PA. We describe the development of this interview and present its test-retest reliability on 15 youth with ID and 20 TD youth.

**Results**—Twenty-three of 33 questions were reliable in both groups. The results suggest that youth with ID can reliably report activities that they do or do not enjoy, as well as their beliefs and perceived benefits of PA.

**Conclusions**—Self-reported information on the experiences, preferences, beliefs, and perceptions about among youth with ID is key for research efforts in health promotion and health disparities.

## Keywords

youth; intellectual disabilities; physical activity; interview; test-retest reliability

## Introduction

Disparities in the health of people with intellectual disabilities (ID) are well-documented (Krahn & Fox 2013; Krahn *et al.* 2006; Reichard *et al.* 2011) and lifestyle factors play an important role in preventing a variety of comorbidities. In particular, participation in regular physical activity (PA) is key to promoting good health and wellbeing for both adults and

youth (Bauman 2004; Janssen & LeBlanc 2010). In general, the majority of youth in the United States do not meet the national guidelines for PA (Song *et al.* 2013), and there is growing evidence that youth with ID may have equally low or even lower levels of PA (Shields *et al.* 2009; Whitt-Glover *et al.* 2006). Youth with ID may experience challenges and barriers to participating in PA that are unique to them and that limit their opportunities for participation in both structured and unstructured activities.

Identifying facilitators and barriers to PA participation is critical for designing effective programs and implementing policies to increase youths' engagement in PA. To date, research examining the correlates of PA in youth with ID has, for the most part, relied heavily on proxy reporting by parents/caregivers rather than on youth themselves (Barr & Shields 2011; Buttimer & Tierney 2005; Foley & McCubbin 2009; Hutzler & Korsensky 2010; Lin et al. 2010; Oates et al. 2011; Rosenberg et al. 2012; Shields et al. 2012). As suggested by Cummins (2002) and corroborated by Glidden et al. (2011) in a recent study of Special Olympics athletes, proxy reporting may not provide an accurate representation of these participants' subjective experiences in sport (Cummins 2002; Glidden et al. 2011). A few instruments have been developed to assess the perceptions of and barriers to exercise in adults with ID (Heller & Prochaska 2001; Heller et al. 2001; Peterson et al. 2009) but to our knowledge, no reliable instruments exist that capture the unique PA experiences of youth with ID. To address this need, we developed an interview instrument to directly query youth with respect to their perceptions about participating in PA, including their enjoyment and preferences, and the factors that impede their participation. The purpose of this report is to describe the development and implementation of an interview on these correlates of PA for youth with ID and to present the test-retest reliability of the interview, with the intent that our experience might serve as an exemplar for including youth with ID themselves in research that is designed to understand their experiences and perceptions.

#### Methods

The interview described in this report was conducted as part of a larger study, the Teens' Recreation and Activity Choices (TRAC) study. TRAC was conducted from 2010 to 2012 at the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School. The overall purpose of the main TRAC study was to compare the PA levels and PA correlates between youth with ID ages 13 to 21 and typically developing (TD) youth of similar ages. Study procedures included a structured interview with youth themselves reporting their PA preferences and perceptions, a joint interview with youth and their parents that queried their PA participation in specific activities, parent completion of a demographic questionnaire, and direct assessment of the youths' PA levels via accelerometry. The present report focuses specifically on the development and reliability of the structured face-to-face interview with the youth themselves that was designed to ascertain their preferences and perceptions of PA, as part of the TRAC study.

Adolescents and their families participating in the study were recruited from Massachusetts and Rhode Island, through public listings via the internet (e.g. Craigslist<sup>™</sup>), outreach to list-servs for families of youth with disabilities, assistance from community recreation programs and special education parent action committees, schools for youth with ID, distributing

flyers at conferences, Special Olympics, an in-house database of participants from previous studies, and word-of-mouth. Inclusion criteria required that the adolescent be in good general health and not have a physical disability that limited participation in PA. Participants were excluded if they did not live at home (i.e., lived in a residential setting), and those with ID were also excluded if they were non-verbal. The Kaufman Brief Intelligence Test 2<sup>nd</sup> edition (KBIT-2) (Kaufman & Kaufman 2004) was administered to confirm an ID diagnosis, which was defined as a composite score of 75. Parents of adolescents with ID completed the Vineland Adaptive Behavior Scales II (VABS-II) (Sparrow *et al.* 2005) to assess their child's developmental, communication, and social skills. The VABS-II was used as a means of characterizing the participants with ID in this study. All parents also completed a demographic questionnaire on participant age, race/ethnicity, and parental education.

Informed consent was obtained from parents and adolescents ages 18 and older. Assent was obtained from adolescents under the age of 18 and those with ID over age 18 who were under their parents' guardianship. All adolescents and parents were compensated for completing the interview, including an additional modest stipend for participation in the reliability study. The study was approved by the Institutional Review Board at the University of Massachusetts Medical School.

As noted, a reliable instrument that assesses physical activity correlates directly from youth with ID has not been developed. Our interdisciplinary team, comprising researchers and clinicians in adapted physical activity, physical therapy, psychology, social work, nutrition, and epidemiology, all of whom have extensive clinical and/or research experience with adolescents with ID and TD adolescents, developed the instrument. We engaged in an iterative process to modify and refine questions to ensure clarity for adolescents with ID. The survey was designed to take the cognitive and language processing difficulties associated with ID into account, and thus contained easily answerable questions that did not require the ability to interpret and/or communicate abstract concepts. Questions were worded simply, and we limited the number of response items to a maximum of three, avoided the need to endorse negative statements affirmatively, and minimized abstract concepts (Finlay & Lyons 2001). The survey composed of close-ended questions to be read aloud to participants with response choices recorded by a trained interviewer. We opted for close-ended questions and simple forced-response choices to enable adolescents with ID to report their answers with ease. To promote understanding and facilitate communication, questions that asked participants to indicate the extent to which they liked activities were accompanied by pictorial representations of response categories, and questions that asked participants for their assessment of their competence/skills in performing activities were accompanied by simply written response categories. Participants were given the option of pointing to response choices rather than responding verbally if that was their preference. For consistency in approach we used the same methods with our comparison group of TD youth, but without the visual aids. Since the study aimed to compare adolescents with ID and TD adolescents, the survey items were those that would be relevant to both groups.

The interview questions were based on the social-ecological model (Bronfenbrenner 1994; Sallis *et al.* 2008), in which facilitators of and barriers to PA are understood to exist as nested, interacting spheres of influence that include individual factors, peer and family

factors, and community-level factors. Constructs from published questionnaires designed to measure correlates of PA among TD youth were also used to guide the selection of individual, family, and community variables included in the interview (Heller et al. 2001; Motl et al. 2001; Sallis et al. 2008; Salmon et al. 2003; Ward et al. 2006; Wu & Pender 2002). Items queried respondents' enjoyment of particular physical activities and sports, including questions about their preferences for the setting and with whom the activities occur, their perceptions of individual and environmental barriers to their participation in PA, their beliefs about PA and its benefits, and their general self-efficacy for PA. Notably, the interview was developed to ascertain the perceptions of both youth with ID and their TD counterparts. Thus, the questions included in the interview were those that would have been applicable to both groups; in other words, we did not include questions that would likely have been endorsed only by youth with ID, such as how cognitive and/or literacy limitations might interfere with one's ability to follow directions or learn to use exercise equipment independently, or how staff may be inadequately trained to support youths' successful participation. In this way, the interview represented an inclusive opportunity to participate in research that would shed light on the experiences of both youth with ID and TD youth.

As part of the development process, the interview was pilot-tested on four adolescents with ID and six TD adolescents to assess the clarity and relevance of the interview questions and to pre-test administration procedures. During pilot study visits, interviewers were observed by other research team members and provided feedback to ensure that interview procedures were carried out consistently. Pilot participants were debriefed following the interview to assess whether any of the questions were confusing or hard to answer, whether the written response choice cards were helpful, and in general, what they thought of the interview. Overall, the interview was well received by both TD and ID pilot participants. Rewording of some questions was based on interviewers' perceptions of the pilot interviews, though none of the participants expressed concerns about the wording. Slight modifications were to promote better flow and/or comprehension. For example, one question that originally read, "*If you had the choice, would you rather do… (a) sports and exercise or (b) other activities?*" was modified to read, "*When you have the choice, what would you rather do in your free time? (a) Sports or exercise; (b) Something else.*"

The final interview consisted of 33 questions. It included eight questions that asked the respondent to rate his or her preference for several activities using a 3-tiered response scale: "Don't like it", "It's okay", or "Like it". Three questions asked about participants' preferences for where and with whom they engage in PA. Twelve two-part questions asked about barriers to PA. The first part of these questions was a Yes/No question that queried whether the participant had ever experienced the barrier. If the participant provided an affirmative response, s/he was asked if the barrier had ever stopped him/her from participating in PA. Two questions asked about whether participants had a pet (considered a facilitator of PA), and whether they walked, biked, ran, or played catch with their pet. Five questions queried the participants' beliefs about PA, and included Yes/No response categories. Finally, three PA self-efficacy questions had response categories of "Not good", "Okay", and "Very good".

The interview was administered on a one-to-one basis by research assistants in a quiet space. Interviewers were trained to deliver questions at a slow pace and to use vocal intonations that would facilitate participants' understanding and processing of the questions. At the same time, care was taken to avoid inadvertently guiding adolescents toward a particular response, such as by providing positive feedback after a response. Participants were provided with cues and/or prompts to redirect their attention during the interview as needed. Interviewers were instructed to mark a question invalid if they judged that the participant failed to grasp the intended meaning of the question. Any question that was flagged as invalid by the interviewer was excluded from further analysis. The interviews lasted approximately 15–20 minutes, on average.

#### Reliability

The goal of the reliability analysis was to assess the test-retest reliability of 33 structured interview questions among both youth with ID and TD youth in order to determine which questions could be used for comparing the correlates of PA in the full study sample. Our sample size of 20 per group was selected based on feasibility and our goal to be able to rank questions by their relative reliability. At the time of the study visit, participants were recruited into the reliability study if they agreed to return for a second interview two to three weeks after the original interview. All youth with ID were invited to participate in the reliability interview; 15 of the 38 participants completed a second interview. The first 20 TD youth (of the total 60 TD participants) who agreed to participate in the reliability interview were enrolled. The test-retest reliability of the adolescent interview was assessed by comparing interview responses from the participants who repeated the interview.

#### Statistical Methods

All of the items in the adolescent interview were categorical variables; therefore, levels of agreement were determined using Kappa coefficients and raw percent agreement. Using the Landis-Koch benchmarks, the Kappa coefficients were considered poor/slight ( $\kappa$ =0.00-0.20), fair ( $\kappa$ =0.21–0.40), moderate ( $\kappa$ =0.41–0.60), substantial ( $\kappa$ =0.61–0.80), or almost perfect (k=0.81-1.0). Kappa values with Fleiss-Cohen weights were used for ordinal comparisons and simple Kappa values were used for nominal comparisons. Because the Kappa statistic exhibits instability when there are a large proportion of responses in one category, it is possible for a question to have a very low or even negative Kappa but a high overall percent agreement. A negative Kappa statistic results when agreement occurs less often than predicted by chance alone. For this reason, we considered a question "reliable" where  $\kappa > 0.60$  and/or percent agreement was 80% or greater, as have others (Hinkley *et al.* 2012). Preference questions that used the 3-tier response scale of "Don't like it", "It's okay", or "Like it" were dichotomized into "don't like it" vs. "Okay/like it". The two-part questions that queried barriers were recoded into a single variable with a 3-tiered response: "No", "Yes, but it doesn't stop me from participating", and "Yes, and it stops me from participating". The 3 self-efficacy questions that used the 3-tier response scale of "Not good", "Okay", or "Very good" were dichotomized into "Not good/okay" vs. "Very good".

Prior research has shown that persons with ID may have an increased tendency to respond to questions in the same pattern or to acquiesce, i.e., answer questions in the affirmative,

regardless of their content (Perry 2004). Accordingly, we conducted a secondary analysis to detect whether youth with ID were more likely to respond affirmatively ("Yes") to questions than TD youth by computing the proportion of "Yes" responses to the questions that were deemed reliable at the first administration.

Analyses were performed in SAS version 9.2 and IBM SPSS Statistics Version 20. A p value of less than 0.05 was used to determine statistical significance.

## Results

Twenty TD youth and 15 youth with mild-to-moderate ID completed the repeat interview which included 33 questions. Table 1 shows the demographic characteristics of the participants. The groups did not differ significantly by age, race/ethnicity, or maximum parental education. The sample was predominantly white and parents were college-educated. Table 2 summarizes the Kappa values by group. Among TD youth, 22 questions (66%) had at least substantial reliability as assessed by the Kappa statistic; 14 questions (42%) showed nearly perfect agreement. Among youth with ID, 14 questions (30%) showed almost perfect agreement.

Applying the criterion of either  $\kappa > 0.60$  or agreement of 80% or higher for declaring a question reliable, only 3 questions (9%) were deemed unreliable among TD youth (Table 3). Among youth with ID, 8 questions (24%) did not meet these criteria. Assessing the reliability criteria for both groups simultaneously (i.e., the question was reliable for *both* TD youth and youth with ID), 23 questions were identified as reliable for comparing responses between the two groups in the overall sample. Of the three questions that were not reliable among youth with TD, one was also not reliable for youth with ID. This question was one of the PA self-efficacy questions: *"How good are you at doing sports and exercise?"* 

Many of the interview questions about participants' preferences were either posed as Yes/No questions or provided a 3-tiered response option (choices: "Like It/It's Okay/Don't Like it") to accommodate the intellectual challenges of the youth with ID. As prior research has suggested, the linguistic and cognitive deficits experienced by individuals with ID make it difficult to assess their point of view, especially when the content is complex or abstract (Perry & Felce 2002). To assess whether participants with ID demonstrated an increased tendency to respond to questions in the affirmative, we computed the proportion of "Yes" responses to the questions that were deemed reliable at the first administration and found no significant differences between TD youth and youth with ID (proportions were 0.74 and 0.72 respectively, p > 0.05).

## Discussion

We sought to develop a structured interview to compare the self-perceived factors associated with PA between youth with and without ID, and to ascertain which of the questions were reliable in test-retest interviewing. The results of the reliability assessment suggest that both youth with mild to moderate ID and TD youth are able to reliably report activities that they do or do not enjoy performing. Likewise, questions tapping beliefs about and benefits of PA

were reliable in both groups. However, questions assessing general self-efficacy for PA proved problematic. Neither youth with ID or TD youth reported reliably on the question, "How good are you at doing sports/exercise?" Youth with ID were not reliable in their response to the question, "How good are you at doing sports and exercise that you do by yourself?" and TD youth did not respond reliably to the question, "How good are you at doing team sports?"

The findings suggest that youth with ID can be interviewed about their preferences and perceptions of their experiences, in this case, about PA. This interview builds on prior literature that seeks to understand the correlates of PA in youth with ID and suggests that youth themselves can be included meaningfully in such efforts. The results also suggest that obtaining reliable answers is more difficult among youth with ID than their TD counterparts, but at the same time, the findings also suggest that reliability is imperfect in both groups. Interestingly, neither group responded reliably to self-efficacy questions, which may have been because the questions were poorly worded or were stated in a global manner that made it difficult for participants to interpret.

As suggested by <sup>Cummins (2002)</sup>, the reliability of proxy reporting for subjective information on behalf of persons with ID diminishes as the behavior or attitudes under question are less directly observable by the proxy. In fact, the extant evidence suggests that proxy reporting may not be a valid technique when attempting to ascertain internal (not observable) variables such as quality of life or subjective well-being (Cummins 2002). With regard to participation in PA, the correlates of which may be complex and intertwined with the individual's self-appraisal of their physical and social circumstances, it remains important to try to capture the individual's direct self-assessment whenever possible.

This interview has several strengths. It was developed using an iterative process with an interdisciplinary team of researchers and clinicians. Pilot-testing afforded an opportunity to assess participants' responses to questions and to refine the questions based on their responses and post-interview feedback. The use of pictures to facilitate the participants' understanding of some response options may have provided support to participants with ID to participate in the interview. The interview was relatively brief, lasting only about 15–20 minutes, so it was not perceived as taxing or burdensome for participants.

Several limitations to the study are noteworthy. We did not conduct the same interview with parents/caregivers; thus, the current analysis does not permit us to assess the convergence or divergence between youth and parental responses. The interview did not contain redundant questions worded in different ways that would have provided an additional method for verifying the consistency of the adolescent's opinions and perceptions; we elected not to add extraneous items in an effort to keep the interview short and clear. We did not employ additional methods to determine the extent to which adolescents with ID understood the questions being asked, though participants were encouraged to ask questions for clarification if they did not understand. Finally, as this interview was part of a larger study concerned with assessing PA levels in youth, we did not collect additional data that could be used to validate the questions asked in the interview. This is an area for future exploration.

Work remains to be done to ascertain the barriers and facilitators to PA that youth with ID experience. More open-ended, qualitative methods may prove useful in discerning some of the factors that we sought to understand in these youth but for which we did not obtain reliable responses, such as whether personal factors such as time, fatigue, enjoyment, and physical comfort are factors that influence participation. Additional factors that may only be experienced by youth with ID would also be important to capture. Future research should focus on developing methods and questions that reliably tap youths' self-efficacy for PA. Nonetheless, despite these limitations, this interview provided a means for assessing the perceptions of PA among youth with ID.

The structured interview provided an important opportunity to learn directly from youth with ID themselves about their perceptions of and experiences with PA. The inclusion of youth with disabilities as active research participants reflects the recognition that assumptions cannot be made about the experiences of people with disabilities, and that they must be involved in research, policy, and clinical endeavors that concern them. The disability community has coined the phrase, "Nothing about us without us" to convey the central role they rightfully play in defining and directing their own lives (Charlton 2000). In contrast to the medical model, the social model of disability views disability are largely seen as a function of societal barriers rather than functional impairments or health conditions per se (Schur *et al.* 2013). In part, our project was designed to assess the personal experiences of youth with ID and to identify individual, social, and community factors that may affect their participation in PA. Attempts to increase the PA in youth with ID must take into account their preferences and perceptions of PA, the circumstances that facilitate or thwart their participation, and the extent to which they feel PA is of benefit to them.

Future research should include questions on the extent to which youth with ID experience social exclusion or other such barriers that prevent their participation in PA. Self-reported information on the experiences, preferences, beliefs, and perceptions about PA among youth with ID is critical for addressing the barriers they may face in acquiring adequate levels of PA. In some cases, they may be vulnerable to the same factors as the general population, in which our built environment and modes of leisure have made it increasingly easy to spend more time in sedentary pursuits (Hill *et al.* 2003). In other ways, however, youth with ID may experience additional barriers such as lack of peers or lack of access to facilities that can include them successfully. In order to address these barriers, and to understand the factors that enable youth to participate, hearing from youth themselves is a critical step in devising programs and access to PA opportunities.

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Characteristics of Study Participants

	TD Youth	(n=20)	TD Youth (n=20) Youth with ID (n=15)	D (n=15)	
	Mean (sd)	(%) U	Mean (sd) n (%) Mean (sd) n (%) p-value	(%) U	p-value
IQ score - KBIT-2	ł	ł	57.5 (11.4)	;	ł
Vineland Adaptive Behavior Composite score <sup><math>a</math></sup>	I	I	67.3 (6.7)	ł	I
Age (y)	15.7 (1.6)	I	16.7 (1.5)	ł	0.09
Male	I	11 (55)	ł	6 (40)	0.38
White Race	I	15 (75)	ł	13 (87)	0.67
Max Parental Education College Degree	I	17 (85)	I	10 (77)	0.66

#### Table 2

#### Summary of Reliability Statistics

	Number of Questions in	n Each Kappa Category
	TD	ID
Poor/Slight (ĸ=0.00-0.20)	1 (3%)	1 (3%)
Fair (ĸ=0.21-0.40)	3 (9%)	5 (15%)
Moderate (ĸ=0.41-0.60)	2 (6%)	6 (18%)
Substantial (ĸ=0.61-0.80)	8 (24%)	4 (12%)
Almost Perfect (ĸ=0.81-1.0)	14 (42%)	10 (30%)

Note: For n=5 (15%) of TD youth and n=7 (21%) of youth with ID, Kappa values were negative or could not be calculated

Table 3

Question-by-Question comparison

	<b>U</b> I	TD (n=20)		D (	ID (n=15)	
	Raw Agreement	Kappa	Reliable	Raw Agreement	Kappa	Reliable
How much do you like:						
1. TV/Videogames	100% (20/20)	1.0	Y	100% (14/14)	1.0	Y
2. Atts & crafts	90% (18/20)	0.76	Y	100% (15/15)	1.0	Y
3. Reading	95% (19/20)	0.77	Y	80% (12/15)	0.29	Y
4. Walking	85% (17/20)	0.32	Υ	80% (12/15)	0.29	Υ
5. Yard/House work	85% (17/20)	0.68	Υ	67% (10/15)	0.34	z
6. Gym class at school	95% (19/20)	ł	Y	87% (13/15)	-0.07	Y
7. Team sports	100% (20/20)	1.0	Y	85% (11/13)	-0.08	Y
8. Solitary sports	95% (19/20)	ł	Y	87% (13/15)	0.42	Y
1. Who would you rather do sports/exercise with	100% (20/20)	1.0	Y	60% (9/15)	0.27	z
2. Where would you rather do sports/exercise	90% (18/20)	0.81	Y	64% (9/14)	0.41	z
3. What would you rather do in your free time	85% (17/20)	0.67	Y	80% (12/15)	0.62	Y
4. Ever too busy for sports/exercise	75% (15/20)	0.82	Y	57% (8/14)	0.03	z
5. Ever too tired for sports/exercise	65% (13/20)	0.18	z	85% (11/13)	0.89	Y
6. Think sports/exercise is boring	70% (14/20)	0.61	Y	77% (10/13)	0.82	Y
7. Afraid of getting hurt during sports/exercise	85% (17/20)	0.78	Y	57% (8/14)	0.42	Z
8. Think sports/exercise are too hard to learn	95% (19/20)	I	Y	86% (12/14)	0.88	Y
9. Think you are good at sports/exercise	90% (18/19)	0.87	Y	93% (14/15)	I	Υ
10. Like how you feel while doing sports/exercise	95% (19/20)	I	Y	100% (15/15)	1.0	Y
11. Bothered by looks while doing sports/exercise	90% (18/20)	0.85	Y	100% (15/15)	1.0	Y
12. Someone to do sports/exercise with	85% (17/20)	-0.05	Y	85% (11/13)	0.86	Υ
13. Do you have a pet	100% (20/20)	1.0	Y	100% (15/15)	1.0	Υ
14. Do you walk/run/play with pet	100% (12/12)	1.0	Y	100% (10/10)	1.0	Y
15. Ever too hot or cold for sports/exercise	85% (17/20)	0.89	Y	38% (5/13)	0.50	z
16. Have a place to do sports/exercise	100% (20/20)	1.0	Y	87% (13/15)	0.59	Y
17. Have a way to get to that place	100% (19/19)	1.0	Y	91% (10/11)	I	Y
18. How much fun do you have doing sports/exercise	80% (16/20)	0.47	Υ	73% (11/15)	0.65	Υ

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	TD	TD (n=20)		<b>D</b>	ID (n=15)	
	Raw Agreement	Kappa	Reliable	Raw Agreement Kappa Reliable Raw Agreement Kappa Reliable	Kappa	Reliable
19. Think sports/exercise are good for you	100% (19/19)	1.0	Υ	87% (13/15)	1	Υ
20. Think sports/exercise is a way to make new friends	100% (20/20)	1.0	Υ	86% (12/14)	0.42	Υ
21. Think sports/exercise will make you feel good	95% (19/20)	0.64	Υ	93% (14/15)	ł	Υ
22. Would like to do more sports/exercise	85% (17/20)	0.32	Υ	93% (14/15)	0.76	Y
23. How good are you at doing sports/exercise	75% (15/20)	0.49	z	67% (10/15)	0.35	z
24. How good are you at doing team sports	70% (14/20)	0.34	z	87% (13/15)	0.70	Υ
25. How good are you at doing sports/exercise you do alone	85% (17/20)	0.68	Υ	40% (6/15)	-0.22	Z