

Supplementary Material 8: Evaluation of the interventions

DOI, authors, title	Effectiveness	Process	Measurement tools	Design of the evaluation	Description of the evaluation	Assessment results	Population evaluated	Outcomes	Evaluation sample size
DOI: 10.1111/jocn.13215 Altundağ, Çalbayram Teaching Menstrual Care Skills to Intellectually Disabled Female Students	Yes	No	Validated measurement tools: pad replacement skills analysis	Pre-post study by observation	Observational measurement of participants' practice, based on observation of interviewers ticking the tool's items (right/right with help/wrong). Before-and-after study to observe changes in scores. A month after the initial skills and training course, pad replacement skills were assessed after the menstrual cycle of each female student. Observation of each student's pad replacement skills. Skills were marked as "done" (two points), "done with aid" (one point) or "failed" (zero points)	Significant increase in tampon use and menstrual management skills (positive change in test scores)	Young people with disabilities	NI*	54
DOI: 10.1007/s11195-015-9424-6 Corona et al. Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents	Yes	Yes satisfaction / utility	Process evaluation: Measuring tools designed for the study: Parent Satisfaction Questionnaire Effectiveness evaluation: Validated measurement tools: Sexual Behavior Scale (SBS) Use of non-validated tools created for the study, such as the Adolescent Knowledge Questionnaire, Parent Questionnaire and the Parent satisfaction questionnaire	Pre-post study	Following the first session, parents completed the Sexual Behavior Scale (SBS), which was developed to measure social and sexual behaviors among adolescents and young adults with ASD. Adolescents completed a ten-question multiple choice questionnaire that contained items about sexuality-related knowledge, as well as knowledge regarding appropriate relationships. A parent questionnaire, developed specifically for the current study, sought to examine which sexuality-related topics parents had previously discussed with their children. Following the final session, parents completed a questionnaire designed to assess parent satisfaction and perceived learning.	Parents reported significantly less total concern following the program Contrary to expectations, no significant difference was found. Parents reported having discussed significantly more topics with their adolescents following the program ($m = 14.13$, $SD = 6.11$). The test revealed no significant difference in parent comfort. Parents reported being highly satisfied with the program. All parents strongly agreed that the program was worth their time and effort	Young people with disabilities and parents of young with disabilities	Social and sexual behaviors Knowledge regarding appropriate relationships	8

DOI: 10.1080/15546128.2020.1831677 Faught et al. Social Boundaries in Young Adult Females with Down Syndrome as a Foundation for Sexuality Education	Yes	No	No measuring tools used	Pre-post study	Before-and-after evaluation of the correct positioning of the people identified on the rainbow (before and after viewing a sex education videos).	Cumulative improvement within each circle ranged from 3.4% to 2,700%. The area of greatest improvement was in the dark red "foreign space" circle, the red "foreign" circle and the orange "vague" circle. Notable differences for certain colors corresponding to certain types of relationship. In the case of very close relationships (blue), the score was already good initially so differences were small	Young people with disabilities	Appropriate social interactions	6
DOI: 10.1007/s11195-019-09582-7 Frank, Sandman Supporting Parents as Sexuality Educators for Individuals with Intellectual Disability: The Development of the Home B.A.S.E. Curriculum	Yes	No	NI*	NI*	The authors are currently conducting a pilot study to test the effectiveness of the Home B.A.S.E. curriculum Quantitative and qualitative data will be collected before, throughout, and after the educational workshop	NI*	Parents of disabled young people	NI*	NI
DOI: 10.1007/s11195-017-9499-3 Graff et al. Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?	Yes	Yes socially validity	Measuring tools designed for the study	Pre-post study	Evaluation for all 3 groups with group control for the first group. A paired sample t test was conducted to compare sexual education knowledge. At the end of the course, a questionnaire was given to all participants in the first two intervention groups as a social validity measure. This questionnaire asked participants to rate on a picture Likert scale their thoughts on the topics as not useful, useful, and very useful.	The acquisition of sex education knowledge for units 1 and 2, and moderate for units 4 and 5. Statistically significant gains in the intervention group but not in the control group Chapters containing information on healthy relationships, red flags in relationships and gender-specific health care were perceived as the most useful by participants. Participants said they would like more information on relationships in general, menstruation, types of abuse, health care and caring for a baby	Young people with disabilities	Knowledge acquired from the intervention	41
DOI: 10.1089/jayao.2018.0025 Granela et al. Sex Education for Children and	Yes	No	Measurement tools designed for the study: Diagnosis questionnaire	Pre-post study	Questionnaire administered prior to intervention at the diagnosis step. Three months after the intervention, the same questionnaire was again administered to measure knowledge acquisition	Before the intervention, only 5 adolescents (25%) demonstrated understanding of the concept of STIs (Q4), compared with 16 (80%) afterwards. Increased identification of STIs and knowledge of birth control Overall increase in knowledge	Young people with disabilities	Knowledge acquisition	20

Adolescents with Type 1 Diabetes in Camagüey Province, Cuba									
DOI 10.1007/s11195-013-9288-6 Hilberink et al. A Pilot Implementation of an Intervention to Promote Sexual Health in Adolescents and Young Adults in Rehabilitation	Yes	Yes Feasibility + satisfaction	Process evaluation: Measuring tools designed for the study: Participants' Satisfaction and Experiences with the Group Program Effectiveness evaluation: Validated measurement tools: the RTP, PDSBES, Trainers' Satisfaction with the Group Program + Dutch National Study on Sexuality "Sex under the age of 25"+GSES	Pre-post study	Satisfaction with the Train-the-Trainer Course (self report) Trainers' Satisfaction with the Group Program (self-report) Participants' Satisfaction and Experiences with the Group Program (to assess their satisfaction with the group program and perceived facilitators and barriers) The Rotterdam transition profile (RTP) [19] measured autonomy in participation in 7 life areas The physical disability sexual and body esteem scale (PDSBES) was used	Mean attendance rate was 83 % (range 69–94 %). The 7 group sessions were generally appreciated positively. No association was found with gender, scales, and site. Pairwise comparison of the PDSBES scales showed no change pre-post-intervention. Participants also showed no change in self-efficacy or need for information. No differences regarding experience with courtship and perceived barriers to sex. Post-intervention, participants reported less difficulty in talking about sex with their (eventual) partner.	Young people with disabilities	NI*	14
DOI: 10.1111/jar.12535 Janeslät et al. An Intervention Using The Parenting Toolkit "Children—What Does It Involve?" and the Real-Care-Baby Simulator among Students with Intellectual Disability—A Feasibility Study	Yes	Yes Feasibility (functionality)	Process evaluation: no Effectiveness evaluation: Validated measurement tools: Infant Simulator Attitude Scale and General Efficacy Scale	Pre-post study	Before-and-after feasibility assessment highlighting the feasibility of the intervention through a qualitative study, and the effectiveness of the intervention through a quantitative study The Infant Simulator Attitude Scale measured insights about parenthood The General Self-Efficacy Scale captured the level of self-efficacy Before and after the intervention, the participants responded to a set of questionnaires. To respond to the research questions, data from two questionnaires used in earlier studies, the report from the RCB simulator (overall performance) and the interviews were used. The teacher performed semistructured interviews based on the questionnaires. The research team also	Difficulties in relation to own needs, difficulties in relation to others, benefits of caring for the RCB simulator. Positive experiences of the RCB simulator Pride when taking care of the RCB simulator Reflections about reproductive life Insights about reproduction	Young people with disabilities	Measure insights about parenthood	6

					collected the postintervention data consisting of the same questionnaire				
DOI: 10.3233/PRM-180547 Levin-Decanini et al. Implementation of Intimate Partner Violence Education for Adolescents with Spina Bifida	Yes	Yes Feasibility (acceptability without description)	NI*	Pre-post study	For two months following the training, adolescent patients were asked to complete a brief survey about their visit. Providers and staff also completed a follow-up survey two months after the training	Increased frequency of relationship conversations Better use of security cards The majority of young people found the safety cards useful Practitioners felt they were able to communicate about IPV since the training (communicating about security and confidentiality)	Young people with disabilities and trainers of young people with disabilities	NI*	13
DOI:10.1177/1362361319842978 Pugliese et al. Feasibility and Preliminary Efficacy of a Parent-Mediated Sexual Education Curriculum for Youth with Autism Spectrum Disorders	Yes	Yes Feasibility and acceptability	Process evaluation: Measuring tools designed for the study: Parent Feedback Questionnaire + Youth Feedback Questionnaire Effectiveness evaluation: Validated measurement tools: Parent Knowledge Questionnaire / Parenting Self Efficacy Scale / POES	Pre-post study with controlled design	Evaluation with parents and young people for 2 intervention groups and 1 control group	Positive feedback from parents on feasibility and acceptability measures The intervention for the young people seemed easy to understand and easily navigable according to their parents, although some topics were more difficult to tackle or explore in greater depth No significant change in parental confidence in discussing sexuality or parental outcome expectancy in discussing sexuality with their children Significant small-medium effect of group on change in youth sexuality knowledge Preliminary efficacy for within-group changes: increased knowledge of parents and young people	Young people with disabilities and parents of young people with disabilities	Assess youth knowledge and attainment of the learning objectives from the curriculum	84
DOI: 10.1080/15546128.2020.1800542 Rooks-Ellis et al. The Effectiveness of a Brief Sexuality Education Intervention for Parents of Children with Intellectual and Developmental Disabilities	Yes	No	Measuring tools designed for the study	Pre-post study	Twenty-six parents completed a pre-post questionnaire and sexuality education training. Parents were provided with information strategies and resources to support sexuality education for their children with intellectual disability	The intervention modified the parents' (1) attitudes and beliefs about sexuality education, (2) level of comfort in communicating about sexuality, and (3) perceived competence for teaching about sexuality	Parents of disabled young people	Attitudes and beliefs about sexuality education Level of comfort in communication / Perceived competence	26

DOI 10.1186/s12888-015-0586-7 Visser et al. Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder <i>NB : The authors have produced an electronic work compiling all the articles published in international journals on this sexual health intervention. For this table, information published in the book has been used to complete some of the information missing from the scientific article included.</i>	Yes	Yes Social validity	Effectiveness evaluation: <u>Measuring tools designed for the study:</u> - psychosexual knowledge test - Self-report scale measuring specific ASD related inappropriate sexual behavior - Parent-reported scale measuring specific ASD related inappropriate sexual behavior <u>Validated measurement tools:</u> - Social Responsiveness Scale (SRS) - The Sex Problems scale of the Child Behavior Checklist Process evaluation: - <i>Satisfaction Questionnaires (SQs)</i> - <i>Adherence measures:</i> 3 measures of protocol adherence were created	Pre-post study controlled	Cognitive outcomes - A psychosexual knowledge test for adolescents of 37 questions - Parents were questioned regarding their estimation of the knowledge of their child using a scale with 10 questions regarding psychosexual knowledge - They create a scale that includes both the ability of the adolescent to recognize and indicate their own as well as other people's boundaries with 7 items for parents Behavioral outcomes - The Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002) was administered to assess potential changes in the social functioning of the adolescents. 65-item questionnaire - Self-perceived romantic relational skills of the adolescents on a 3-item scale - The Sex Problems scale of the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013) to determine changes in psychosexual problems. - Self-report scale measuring specific ASD-related inappropriate sexual behavior Parent-reported scale measuring specific ASD-related inappropriate sexual behavior Social validity: - <i>Characteristics of the Satisfaction Questionnaires (SQs)</i> for adolescents and parents. 16 questions on how they appreciated several procedures of the training program. SQs for professionals contained 30 questions in addition to questions regarding their satisfaction with procedures of the TTT program - <i>Adherence measures:</i> 3 measures of protocol adherence. The first	Cognitive outcomes - Adolescents in the intervention condition demonstrated a significantly greater increase in psychosexual knowledge - Parent-reported knowledge of their child increased significantly more in the intervention condition than in the control condition - A significant treatment effect was found on the parent-reported scale measuring adequate boundaries - Following the TTT program resulted in significantly more increase in parent-reported insight in adequate boundaries for adolescents in the intervention condition than adolescents in the control condition Behavioral outcomes - Adolescents in both conditions significantly increased their social functioning over time, irrespective of condition - Significant main effects for time were also found on the Sex Problems scale of the CBCL - Decreased problematic sexual behavior in all participating adolescents, irrespective of condition - No significant treatment effects were found on the SRS total score, the self-reported romantic relational skills scale, the Sex Problems scale of the CBCL, nor on the self-reported and parent-reported inappropriate sexual behavior scale Social validity: - High overall satisfaction with the TTT program	Young people with disabilities and parents of young people with disabilities	Cognitive outcomes and behavioral outcomes	189
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					measure was the adjustment of the order of the sessions. The second measure was the number of adjusted exercises, and the third measure was the number of skipped mandatory exercises	- Adolescents very satisfied with their contact with the professional and the opportunity to ask questions - Parents also very satisfied with their contact with the professional and the opportunity to ask questions - The protocol adherence forms showed that in 14 of the 83 (16.9%) completed training programs the order of the sessions was adjusted by the professional			
DOI: 10.1007/s11195-016-9465-5 Yıldız, Cavkaytar Effectiveness of a Sexual Education Program for Mothers of Young Adults with Intellectual Disabilities on Mothers' Attitudes Toward Sexual Education and the Perception of Social Support	Yes	Yes Social validity	Process evaluation: Measuring tools designed for the study Effectiveness evaluation: Validated measurement tools: Family Needs Survey (FNS), adapted + SEIDAS + RPSSS	Pre-post study with control group	The Family Needs Survey (FNS) was used. To assess the effectiveness of the SEPID developed in accordance with the needs analysis, the Sexuality Education of Individuals with Intellectual Disabilities Attitude Scale (SEIDAS) and the Revised Parental Social Support Scale (RPSSS) were utilized. The FNS includes 29 items, the SEIDAS 16 and the RPSSS 31 items The three surveys used a Likert-type scale In addition, a 10-item social validity survey was developed by the first author to obtain participant views on the purpose, content, method and findings of the study (3-point Likert-type scale)	Social validity considered as good: parents satisfied by the intervention Experimental group obtained better results compared with the control group Attitudes of the participants toward sexuality education were related to the group (experimental/control) to which they belonged	Parents of disabled young people	Sexual behavior	44

* NI = no information.