Title:

In a study with adolescents with intellectual disability, drop-out during the study is associated with higher participant burden, while drop-out at study exit is associated with characteristics of the carer and household but not the adolescent.

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Conflict of interest

Uniquist, a corporate arm of the University of Queensland licenses the Comprehensive Health Assessment Program (CHAP). The trial that this data originated from tested a health intervention consisting of classroom-based education, a health diary, and a health check. The CHAP was the health check investigated in the wider RCT. The royalties from the CHAP license are shared equally between the University of Queensland, the Queensland Centre for Intellectual and Developmental Disability, and the third author (Nicholas G. Lennox). The first author (Robert S. Ware) and second author (Lyn McPherson) have no competing interests.

Submission Declaration

The submitted work has not been published previously in any form, it is not under consideration for publication elsewhere, its publication has been approved by all authors, and, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder.

Authorship

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the submitted version.

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ABSTRACT

Objective: People with intellectual disability are difficult to retain in longitudinal studies. Research on determinants of study retention for individual-carer dyads, and their reasons for drop-out, are limited. The aim of this study was to investigate characteristics associated with drop-out, and to investigate whether characteristics varied by stage of drop-out.

Study Design and Setting: Data are from an Australian randomized trial with adolescents with intellectual disability living in the community. Characteristics of both the adolescent and their nominated carer were collected at baseline. Carers were sent an exit questionnaire approximately two years after enrolment.

Results: Baseline information was available for 566 adolescents: 72(13.0%) withdrew during the study, and 96(17.3%) didn't return exit questionnaires. Characteristics associated with drop-out during the study were being in the intervention group, the carer being younger, and the carer not being one of the adolescent's parents. Characteristics associated with withdrawal at exit were carer having lower education and carer having lower socioeconomic status. No adolescent characteristic was associated with drop-out.

Conclusion: Characteristics of drop-outs weren't related to the adolescent and differed according to timing. Drop-out during the study was associated with study burden, whereas characteristics of drop-outs at exit interview were associated with lower social position.

Keywords: intellectual disability; epidemiologic methods; health surveys; questionnaires; nonresponse; data collection.

What is new?

- In a two-year longitudinal study of adolescents with intellectual disability, drop-out was related to carer, household, and study characteristics but not adolescent characteristics
- Drop-out during the study was associated with higher study burden
- Drop-out at study exit was associated with lower social position
- When designing interventions studies, researchers should focus on designing interventions with similar participant burden in all comparison groups to avoid differential drop-out

1. Introduction

People with intellectual disability have poorer health and shorter lifespans than the general population, as well as high levels of unrecognized disease and inadequate health screening and promotion [1-3]. Despite this health disparity few large epidemiological studies concerning the health of people with intellectual disability have been conducted [4,5]. Recruitment and retention in this population is logistically difficult and resource intensive compared to their peers in the general population [6,7]. Extra difficulties include the need for proxy consent when the individual does not have the capacity to provide informed consent [8], the number of gatekeepers that may need to be approached including clinicians, support workers and family members and carers [7], and, should the disability have a genetic cause, the increased likelihood that the family member providing consent may have limited literacy skills. The extensive recruitment efforts required can be expensive making it more financially important to retain participants than in studies of non-disabled populations.

The topic of participant retention in longitudinal studies has received a significant amount of attention in the past decade. For example in the general population, participant retention is associated with female gender [9-11], higher education [11,12], older age [9,12], being married [13], and belief in the importance of the studied topic [14], while strategies that successfully increase retention rates include extra participant contact, offering participants unconditional incentives, and pre-notification phone calls [15]. However there is little published information available on study retention in people with intellectual disability [16]. In particular it is not known whether the characteristics of the person, or their carer, or both, are most likely to influence the likelihood of successfully completing the study. In order to retain participants and their carers in research studies, and hence maintain a study's internal validity, it is important to know what factors are likely to be associated with retention, so that some categories of participants can be specifically targeted for cohort maintenance.

An Australian academic research center has run a large randomized trial investigating a health intervention package in adolescents with intellectual disability living in the community. At study entry the adolescent's nominated carer completed a questionnaire survey. The same carer was invited to complete a follow-up questionnaire at study completion approximately two years later. The aim of this study was to assess the association between adolescent and carer characteristics and participation at follow-up.

2. Methods

The Ask Study is a parallel-group cluster randomized controlled trial undertaken among adolescents with intellectual disability attending secondary school and living in the community in Southern Queensland, Australia, between February 2007 and September 2010 (ClinicalTrials.gov identifier: NCT00519311) [17]. Adolescents eligible to participate in the Ask study were identified through their enrolment at a Special Education School (SES) or Special Education Unit (SEU). SESs are segregated and are attended by children with more significant care needs, while SEUs are located on the campus of a mainstream school. Participants had been assessed by Education Queensland to have an intellectual disability, and were aged 10-18 years on 1 January, 2006. The intervention assessed was a health intervention package, comprising classroom-based health education, a health check, and a health diary for use by the adolescent, their parents/carers and GPs, compared with usual education and medical care. Units of randomization were schools. Ethics approval was granted by both the University of Queensland Behavioral and Social Sciences Ethical Review Committee (#2004000081) and the Queensland Government Department of Education and the Arts (#550/27/424). Individual consent to participate was gained from the adolescent's carer.

Baseline questionnaires were sent to the adolescent's carer upon study enrolment. Exit questionnaires were sent approximately two years after baseline to the last known address of carers who had not withdrawn during the course of the study. Schools were contacted for updated contact details when necessary. Participants were categorized according to their stage of drop-out as either returned exit questionnaire, failed to return exit questionnaire, or withdrew before exit questionnaire was distributed.

Telephone interviews were offered at baseline to allow for parents with low literacy for whom responding to a paper-based questionnaire might be problematic. Questionnaires were posted to the participant's residential address. Four weeks after the initial mail-out study staff began making follow-up phone calls to prompt potential participants to return their questionnaires. All carers who had not responded received at least two reminder calls. When carers were contacted by phone the option of a telephone interview was offered (either immediately or at a time of the carer's choosing). Carers were not systematically targeted for telephone interview. Baseline return status was categorized as either postal returner (returned

questionnaire without phone call), postal returner after phone prompt or telephone responder (completed questionnaire by telephone).

The baseline and exit questionnaires were the same for both intervention and usual care groups, with the addition of questions regarding the usability and benefits of the health intervention package for the intervention group in the exit. Baseline questionnaires asked the age and sex of the adolescent, the etiology of their intellectual disability, and their abilities, and for an assessment of their health. Information on the adolescent's carer and household characteristics, including the adolescents living situation (living with two parents/living with one parent/living with adults other than parents), and the carers reasons for participating in the study were collected. The adolescent's behavioral problems were assessed using the Short Form of the Developmental Behavior Checklist, with adolescents categorized as having no, minor or major problems using pre-defined cut-points of 0.48 and 0.83 [18,19]. Social position was measured at the postcode level using the Australian Bureau for Statistics Socio-Economic Index For Areas of Relative Disadvantage [20]. Trial characteristics recorded were whether the adolescent was allocated to the intervention (yes/no), carer's reason for participating, and baseline return status.

Summary statistics are presented as frequency (percentage). Associations between adolescent/carer characteristics and phase of drop-out were investigated using logistic regression analysis. First univariable analyses were conducted, and then multivariable analyses with adjustment for variables that were univariably significant by the likelihood ratio test. Effect estimates are summarized as odds ratios (OR) and 95% confidence intervals (95%CI). Statistical analyses were undertaken using Stata statistical software v14.0 (StataCorp, College Station, TX, USA).

3. Results

Of the 592 carers who completed the baseline questionnaire, consent to access medical records could not be obtained from the adolescent's family physician for 26 corresponding adolescents (4.4%) and they were excluded from the study. Of the remaining 566 participants, 72 (13.0%) withdrew before exit questionnaires were distributed, 96 (17.3%) were sent exit questionnaires but did not return them, and 388 (69.8%) returned exit questionnaires.

Demographic and clinical characteristics of the adolescents with intellectual disability are summarized in Supplementary Table 1. There were no characteristics of the adolescent multivariably associated with drop-out. Carer, household, and trial characteristics are displayed in Supplementary Table 2. Characteristics identified as being significantly associated with drop-out (at any stage) were carer age and education, social position, living situation, and intervention status. All multivariable models were adjusted for these characteristics. Carer characteristics associated with higher drop-out, after adjusting for potentially confounding variables, included being aged 20-39 years compared with age 40-49 years (OR=2.1;95%CI=1.1-4.1), and not completing high school (OR=2.0;95%CI=1.3-3.0). Household characteristics associated with higher drop-out were being located in an area ranked in the lowest fifth for social position, rather than the middle fifth (OR=2.2;95%CI=1.2-4.1), and the adolescent residing with a non-parent carer compared with living in a two-parent household (OR=2.8;95%CI=1.2-6.6). Somewhat surprisingly, carers of adolescents allocated to the intervention were more likely not to complete the exit questionnaire (OR=1.8;95%CI=1.2-2.7). Other trial characteristics, including the carer's motivation for participating in the study, did not affect likelihood of successful follow-up.

When the association between characteristics and the stage of drop-out was considered, there remained no association between adolescent characteristics and study drop-out (Table 1). When carer, household, and trial characteristics were considered (Table 2), the strongest indicator of being likely to withdraw during the study before exit questionnaires were sent was being allocated to the intervention group (OR=4.9;95%CI=2.4-9.9). Other significantly associated characteristics were being aged 20-39 rather than 40-59 (OR=2.5;95%CI=1.0-6.6), and residing with a non-parent carer compared with living in a two-parent household (OR=3.2;95%CI=1.1-9.0). When considering characteristics of carers who did not return exit questionnaires, residing in an area ranked in the lowest fifth for social position, rather than the middle fifth (OR=2.8;95%CI=1.8-8.1), and the carer not finishing high school (OR=2.5;95%CI=1.4-5.0) were the only characteristics significantly associated with drop-out.

Table 1: Adolescent characteristics at baseline according to stage of drop-out (N=388 returned questionnaire; N=72 withdrew before exit interview, N=96 did not return exit interview)

	N	Returned exit questionnaire	Withdrew during study	Unadjusted OR (95%CI)	Adjusted OR (95%CI)	Did not return exit questionnaire	Unadjusted OR (95%CI)	Adjusted OR (95%CI)
Total participants	556	388 (69.8%)	72 (13.0%)			96 (17.3%)		
Age (years)								
<=14	210	146 (69.5%)	31 (14.8%)	1.0	1.0	33 (15.7%)	1.0	1.0
15-16	230	162 (70.4%)	26 (11.3%)	0.8 (0.4, 1.3)	0.9 (0.5, 1.7)	42 (18.3%)	1.1 (0.7, 1.9)	1.2 (0.7, 2.0)
>=17	116	80 (69.0%)	15 (12.9%)	0.9 (0.5, 1.7)	1.2 (0.6, 2.4)	21 (18.1%)	1.2 (0.6, 2.1)	1.3 (0.7, 2.4)
Sex								
Male	295	206 (69.8%)	38 (12.9%)	1.0	1.0	51 (17.3%)	1.0	1.0
Female	261	182 (69.7%)	34 (13.0%)	1.0 (0.6, 1.6)	1.1 (0.6, 1.8)	45 (17.2%)	1.0 (0.6, 1.6)	0.9 (0.6, 1.5)
Cause of disability								
Down Syndrome	73	59 (80.8%)	5 (6.9%)	0.4 (0.1, 1.0)	0.5 (0.2, 1.3)	9 (12.3%)	0.6 (0.3, 1.4)	0.8 (0.3, 1.6)
Other syndrome	312	212 (68.0%)	49 (15.7%)	1.0	1.0	51 (16.4%)	1.0	1.0
Unknown	171	117 (68.4%)	18 (10.5%)	0.7 (0.4, 1.2)	0.7 (0.4, 1.4)	36 (21.1%)	1.3 (0.8, 2.1)	1.3 (0.8, 2.1)
School type								
Special Education Unit	292	211 (72.3%)	37 (12.7%)	1.0	1.0	44 (15.1%)	1.0	1.0
Special Education School	264	177 (67.1%)	35 (13.3%)	1.1 (0.7, 1.9)	1.0 (0.6, 1.8)	52 (19.7%)	1.4 (0.9, 2.2)	1.3 (0.8, 2.0)
General Health								
Excellent	158	110 (69.6%)	22 (13.9%)	1.0	1.0	26 (16.5%)	1.0	1.0
Very Good	178	133 (74.7%)	15 (8.4%)	0.6 (0.3, 1.1)	0.6 (0.3, 1.2)	30 (16.9%)	0.9 (0.5, 1.7)	1.0 (0.6, 1.9)
Good	164	108 (65.9%)	28 (17.1%)	1.3 (0.7, 2.4)	1.2 (0.6, 2.4)	28 (17.1%)	1.1 (0.6, 2.0)	1.2 (0.6, 2.2)
Fair/Poor	56	37 (66.1%)	7 (12.5%)	0.9 (0.4, 2.4)	0.9 (0.3, 2.5)	12 (21.4%)	1.4 (0.6, 3.0)	1.5 (0.7, 3.3)
Physical Mobility								
Completely Independent	481	333 (69.2%)	64 (13.3%)	1.0	1.0	84 (17.5%)	1.0	1.0
Independent with help	38	30 (79.0%)	3 (7.9%)	0.5 (0.2, 1.8)	0.6 (0.2, 2.3)	5 (13.2%)	0.7 (0.2, 1.8)	0.7 (0.3, 1.9)
Uses wheelchair/immobile	37	25 (67.6%)	5 (13.5%)	1.0 (0.4, 2.8)	0.8 (0.3, 2.2)	7 (18.9%)	1.1 (0.5, 2.7)	1.1 (0.5, 2.8)
Communication								
Mainly/Entirely verbal	424	287 (67.7%)	60 (14.2%)	1.0	1.0	77 (18.2%)	1.0	1.0
Verbal with nonverbal aids	75	56 (74.7%)	8 (10.7%)	0.7 (0.3, 1.5)	0.6 (0.3, 1.5)	11 (14.7%)	0.7 (0.4, 1.5)	0.7 (0.4, 1.5)
Mainly nonverbal/facilitated	57	45 (79.0%)	4 (7.0%)	0.4 (0.1, 1.2)	0.4 (0.1, 1.2)	8 (14.0%)	0.7 (0.3, 1.5)	0.7 (0.3, 1.6)
Behavior Problems								
No	176	123 (69.9%)	18 (10.2%)	1.0	1.0	35 (19.9%)	1.0	1.0
Minor	186	126 (67.7%)	27 (14.5%)	1.5 (0.8, 2.8)	1.5 (0.8, 3.0)	33 (17.7%)	0.9 (0.5, 1.6)	0.9 (0.5, 1.5)
Major	189	136 (72.0%)	27 (14.3%)	1.4 (0.7, 2.6)	1.4 (0.7, 2.7)	26 (13.8%)	0.7 (0.4, 1.2)	0.6 (0.3, 1.1)

Table 2: Carer, household and trial characteristics at baseline according to stage of drop-out (N=388 returned questionnaire; N=72 withdrew before exit interview, N=96 did not return exit interview)

Characteristic	N	Returned exit questionnaire	Withdrew during study	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Did not return exit questionnaire	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Carer characteristics								
Relationship to adolescent								
Parent	512	364 (71.1%)	63 (12.3%)	1.0	1.0	85 (16.6%)	1.0	1.0
Other	44	24 (54.6%)	9 (20.5%)	2.2 (1.0, 4.9)	1.6 (0.4, 6.3)	11 (25.0%)	2.0 (0.9, 4.2)	2.5 (0.9, 7.0)
Age (years)								
20-39	128	70 (54.7%)	28 (21.9%)	3.4 (1.9, 6.3)	2.5 (1.0, 6.6)	30 (23.4%)	1.9 (1.1, 3.2)	1.9 (0.8, 4.2)
40-49	288	214 (74.3%)	25 (8.7%)	1.0	1.0	49 (17.0%)	1.0	1.0
50+	130	98 (75.4%)	16 (12.3%)	1.4 (0.7, 2.7)	2.0 (0.6, 6.6)	16 (12.3%)	0.7 (0.4, 1.3)	0.7 (0.3, 1.8)
Gender								
Female	479	332 (69.3%)	58 (12.1%)	1.0	1.0	89 (18.6%)	1.0	1.0
Male	75	55 (73.3%)	13 (17.3%)	1.4 (0.7, 2.6)	1.5 (0.8, 3.2)	7 (9.3%)	2.1 (0.9, 4.8)	1.9 (0.8, 4.5)
Education								
Finished high school Yr-12	175	242 (65.6%)	19 (10.9%)	1.0	1.0	17 (9.7%)	1.0	1.0
Did not finish high school Yr-12	369	139 (79.4%)	50 (13.6%)	1.4 (0.8, 2.5)	1.4 (0.8, 2.5)	77 (20.9%)	2.5 (1.4, 5.0)	2.5 (1.4, 5.0)
Attended special school								
No	509	359 (70.5%)	65 (12.8%)	1.0	1.0	85 (16.7%)	1.0	1.0
Yes	41	24 (58.5%)	6 (14.6%)	1.4 (0.5, 3.5)	1.6 (0.6, 4.4)	11 (26.8%)	1.9 (0.9, 4.1)	1.9 (0.9, 4.2)
English as first language								
Yes	524	365 (69.7%)	67 (12.8%)	1.0	1.0	92 (17.6%)	1.0	1.0
No	29	21 (72.4%)	4 (13.8%)	1.0 (0.3, 3.1)	0.7 (0.2, 2.3)	4 (13.8%)	0.8 (0.3, 2.3)	0.8 (0.3, 2.4)
Household characteristics								
Social position (fifths)								
Lowest	63	32 (50.8%)	9 (14.3%)	1.2 (0.5, 2.8)	1.0 (0.4, 2.5)	22 (34.9%)	3.5 (1.7, 7.3)	2.8 (1.8, 8.1)
Lower	127	89 (70.1%)	18 (14.2%)	0.9 (0.4, 1.7)	0.8 (0.4, 1.7)	20 (15.8%)	1.1 (0.6, 2.3)	1.2 (0.6, 2.5)
Middle	139	97 (69.8%)	23 (16.6%)	1.0	1.0	19 (13.7%)	1.0	1.0
Higher	123	88 (71.5%)	11 (8.9%)	0.5 (0.2, 1.1)	0.7 (0.3, 1.6)	24 (19.5%)	1.4 (0.7, 2.7)	1.6 (0.8, 3.2)
Highest	104	82 (78.9%)	11 (10.6%)	0.6 (0.3, 1.2)	0.7 (0.3, 1.6)	11 (10.6%)	0.7 (0.3, 1.5)	0.8 (0.4, 1.9)
Area of residence								
Regional	277	192 (69.3%)	38 (13.7%)	1.0	1.0	47 (17.0%)	1.0	1.0
Major city	279	196 (70.3%)	34 (12.2%)	0.9 (0.5, 1.5)	0.8 (0.5, 1.4)	49 (17.6%)	1.0 (0.7, 1.6)	1.1 (0.7, 1.7)
Living situation								
living with 2 parents	378	271 (71.7%)	49 (13.0%)	1.0	1.0	58 (15.3%)	1.0	1.0

living with 1 parent	151	103 (68.2%)	15 (9.9%)	0.8 (0.4, 1.5)	0.8 (0.4, 1.6)	33 (21.9%)	1.5 (0.9, 2.4)	1.5 (0.9, 2.4)
living with other carers	25	12 (48.0%)	8 (32.0%)	3.7 (1.4, 9.5)	3.2 (1.1, 9.0)	5 (20.0%)	1.9 (0.7, 5.7)	2.5 (0.8, 7.9)
Trial characteristics								
Allocated to intervention								
No	234	181 (77.4%)	10 (4.3%)	1.0	1.0	43 (18.4%)	1.0	1.0
Yes	322	207 (64.3%)	62 (19.3%)	5.4 (2.7, 10.9)	4.9 (2.4, 9.9)	53 (16.5%)	1.1 (0.7, 1.7)	1.1 (0.7, 1.7)
Reason for participating								
Interventions good idea	229	157 (68.6%)	29 (12.7%)	1.0	1.0	43 (18.8%)	1.0	1.0
Asked by school	222	153 (68.9%)	29 (13.1%)	1.0 (0.6, 1.8)	1.2 (0.7, 2.2)	40 (18.0%)	1.0 (0.6, 1.5)	1.0 (0.6, 1.7)
Concern about child's health	46	34 (73.9%)	7 (15.2%)	1.1 (0.5, 2.8)	1.5 (0.6, 3.9)	5 (10.9%)	0.5 (0.2, 1.5)	0.5 (0.2, 1.5)
To help child/others	29	24 (82.8%)	3 (10.3%)	0.7 (0.2, 2.4)	0.9 (0.2, 3.4)	2 (6.9%)	0.3 (0.1, 1.3)	0.3 (0.1, 1.5)
Baseline return status								
Postal returner	262	194 (74.1%)	31 (11.8%)	1.0	1.0	37 (14.1%)	1.0	1.0
Postal return after prompt	159	103 (64.8%)	26 (16.4%)	1.6 (0.9, 2.8)	1.5 (0.8, 2.7)	30 (18.9%)	1.5 (0.9, 2.6)	1.6 (0.9, 2.7)
Telephone interview	135	91 (67.4%)	15 (11.1%)	1.0 (0.5, 2.0)	1.0 (0.5, 2.0)	29 (21.5%)	1.7 (1.0, 2.9)	1.6 (0.9, 2.8)

4. Discussion

Adolescent, carer, household, and trial characteristics were examined with regards to their completion of an exit questionnaire more than two years after study entry in a sample of adolescents with intellectual disability living in the community. Successful completion of the follow-up questionnaire was far more influenced by carer, household and trial characteristics than adolescent characteristics; in particular carers who were younger, who had lower social position and education, and who were not one of the adolescent's parents were less likely to complete the exit questionnaire. Carers of individuals allocated to the intervention group were more likely to drop-out of the study. Likely reasons for drop-out can be observed when considering the stage of drop-out. In particular, characteristics associated with drop-out during the study were younger carer age, the carer not being a parent, and the adolescent being allocated to the intervention group. These withdrawals are likely to be associated with the extra burden on carers in the intervention group during the intervention phase of the study, and the extra contact from study investigators that intervention group carers received when prompted to take their adolescent for a health check, compared to the little or no contact received by the carers of adolescents allocated to the usual care group. Requiring participants to attend their general practitioner for a health check may have been too invasive or difficult for some participants, and led to the extra loss in the health intervention group. Characteristics associated with drop-out during the exit interview phase were lower social position and lower education, both attributes that are conventionally associated with lower likelihood of survey participation in the general population [12].

Results of this study have practical applications for researchers. First, this information may be used to keep adolescents and their carer's with a high risk for dropping out in the study, for example, by considering study designs that impose the minimum amount of burden of carers – or at least designing studies that impose similar burdens on individuals in the intervention and usual care groups to ensure burden-related drop-out is not differentially biased. Second, if researchers choose to adjust for missing data by using imputation or modelling methods, they need to make assumptions about the characteristics of subjects who do not respond. By considering the difference in characteristics by participation status, these results can inform more sophisticated analyses.

Strengths of this study include the comprehensive attempts made to enroll participants at baseline, ensuring that participants included a wide selection of adolescents with intellectual disability, and that all factors of the disability spectrum were covered. These efforts resulted in a very large sample size for a study in this population. Participants were similar in age and gender to the population of high-school students with intellectual disability from which they were drawn, suggesting they may be generalizable to the wider population of school-attending adolescents with intellectual disability living in the community in both Australia and other developed countries [21]. Other factors may have influenced the drop-out rate in this study which may not necessarily influence the participation rates of other studies involving people with intellectual disability. Cleaver [16] suggested that the ability of an investigator to directly contact a participant, the method of obtaining consent and the invasiveness of the data collection can influence participation. As this sample was recruited through schools, which contributed to an extended consent process, which may have had an adverse effect on participation as we have previously reported [17], the level of contact with participants was reduced, which may have reduced the overall participation rate but there is no reason to believe that this would have biased the results.

In summary, a select group of carers returned exit questionnaires – carers who were younger, of lower social position, and who had greater study burden were less likely to remain in the study. Characteristics of carers who dropped out differed according to the stage of the study, with drop-out according to study burden much higher in intervention than control group participants. These findings should be considered when addressing potential biases introduced by nonresponding participants and when determining which participants should be specifically targeted to curb participant losses in future studies of people with intellectual disability.

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Further information on the Ask Study, including on all components of the interventions, and data access can be obtained by contacting the authors at qcidd@uq.edu.au.

Supplementary Table 1: Adolescent characteristics at baseline according to exit interview status (N=556)

	N	Did not complete exit interview	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Total number of participants	556	168 (30.2%)		
Age (years)				
<=14	210	64 (30.5%)	1.0	1.0
15-16	230	68 (29.6%)	1.0 (0.6, 1.4)	1.1 (0.7, 1.7)
>=17	116	36 (31.0%)	1.0 (0.6, 1.7)	1.2 (0.7, 2.0)
Sex				
Male	295	89 (30.2%)	1.0	1.0
Female	261	79 (30.3%)	1.0 (0.7, 1.4)	1.0 (0.7, 1.4)
Cause of disability				
Down Syndrome	73	14 (19.2%)	0.5 (0.3, 0.9)	0.6 (0.3, 1.2)
Other syndrome	312	120 (36.1%)	1.0	1.0
Unknown	171	54 (31.6%)	1.0 (0.7, 1.5)	1.0 (0.7, 1.5)
School type				
Special Education Unit	292	81 (27.7%)	1.0	1.0
Special Education School	264	87 (33.0%)	1.3 (0.9, 1.8)	1.2 (0.8, 1.7)
General Health				
Excellent	158	48 (30.4%)	1.0	1.0
Very Good	178	45 (25.3%)	0.8 (0.5, 1.3)	0.8 (0.5, 1.3)
Good	164	56 (34.2%)	1.2 (0.7, 1.9)	1.2 (0.7, 1.9)
Fair/Poor	56	19 (33.9%)	1.2 (0.6, 2.3)	1.1 (0.6, 2.3)
Physical Mobility				
Completely Independent	481	148 (30.8 %)	1.0	1.0
Independent with help	38	8 (21.1 %)	0.6 (0.3, 1.3)	0.7 (0.3, 1.5)
Uses wheelchair/immobile	37	12 (32.4 %)	1.1 (0.5, 2.2)	0.9 (0.4, 2.0)
Communication				
Mainly/Entirely verbal	424	137 (32.1%)	1.0	1.0
Verbal with nonverbal aids	75	19 (25.3%)	0.7 (0.4, 1.2)	0.7 (0.4, 1.3)
Mainly nonverbal/facilitated	57	12 (21.1%)	0.6 (0.3, 1.1)	0.6 (0.3 1.1)
Behavior Problems				
No	176	53 (30.1%)	1.0	1.0
Minor	186	60 (32.3%)	1.1 (0.7, 1.7)	1.0 (0.6, 1.6)
Major	189	53 (28.0%)	0.9 (0.6, 1.4)	0.8 (0.5, 1.3)

**Supplementary Table 2: Carer, household and trial characteristics at baseline
according to exit interview status (N=556)**

	N	Did not complete exit interview	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Carer characteristics				
Relationship to adolescent				
Parent	512	148 (28.9%)	1.0	1.0
Other	44	20 (45.5%)	2.0 (1.1, 3.8)	2.1 (0.9, 4.9)
Age (years)				
20-39	128	58 (45.3%)	2.4 (1.5, 3.7)	2.1 (1.1, 4.1)
40-49	288	74 (25.7%)	1.0	1.0
50+	130	32 (24.6%)	0.9 (0.6, 1.5)	1.1 (0.5, 2.3)
Gender				
Male	75	20 (26.7%)	1.2 (0.7, 2.1)	1.1 (0.6, 2.0)
Female	479	147 (30.7%)	1.0	1.0
Education				
Finished high school year 12	175	36 (20.6%)	1.0	1.0
Did not finish high school year 12	369	127 (34.4%)	2.0 (1.3, 3.0)	2.0 (1.3, 3.0)
Attended special school				
No	509	150 (29.5%)	1.0	1.0
Yes	41	17 (41.5%)	1.7 (0.9, 3.2)	1.8 (0.9, 3.6)
English as first language				
Yes	524	159 (30.3%)	1.0	1.0
No	29	8 (27.6%)	0.9 (0.4, 2.0)	1.1 (0.4, 2.5)
Household characteristics				
Social position (fifths)				
Lowest	63	31 (49.2%)	2.2 (1.2, 4.1)	2.2 (1.2, 4.1)
Lower	127	38 (29.9%)	1.0 (0.6, 1.7)	1.0 (0.6, 1.8)
Middle	139	42 (30.2%)	1.0	1.0
Higher	123	35 (28.5%)	0.9 (0.5, 1.6)	1.1 (0.6, 2.0)
Highest	104	22 (21.2%)	0.6 (0.3, 1.1)	0.7 (0.4, 1.4)
Area of residence				
Regional	277	85 (30.7%)	1.0	1.0
Major city	279	83 (29.8%)	1.0 (0.7, 1.4)	0.9 (0.6, 1.3)
Living situation				
living with 2 parents	378	107 (28.3%)	1.0	1.0
living with 1 parent	151	48 (31.8%)	1.2 (0.8, 1.8)	1.2 (0.8, 1.8)
living with other carers	25	13 (52.0%)	2.7 (1.2, 6.2)	2.8 (1.2, 6.6)
Trial characteristics				
Allocated to intervention				
No	234	53 (22.7%)	1.0	1.0
Yes	322	115 (55.7%)	1.9 (1.3, 2.8)	1.8 (1.2, 2.7)
Reason for participating				
Think interventions good idea	229	72 (31.4%)	1.0	1.0
Asked by school	222	69 (31.1%)	1.0 (0.7, 1.5)	1.1 (0.7, 1.7)
Concerns about health of child	46	12 (26.1 %)	0.8 (0.4, 1.6)	0.9 (0.4, 1.8)
To help child/others	29	5 (17.2%)	0.5 (0.2, 1.2)	0.5 (0.2, 1.5)
Baseline return status				
Postal returner	262	68 (26.0%)	1.0	1.0
Postal return after prompt	159	56 (35.2%)	1.6 (1.0, 2.3)	1.5 (1.0, 2.4)
Telephone interview	135	44 (32.6%)	1.4 (0.9, 2.1)	1.3 (0.8, 2.2)

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