

Table S1. Demographic, social, and clinical characteristics of participants in the Ask study who completed CHAP health check booklets (n = 176).

| Characteristic | Total (n, %) | Special Education School (n, %) | Special Education Unit in mainstream school (n, %) |
|---|--------------|---------------------------------|--|
| Age (years) | | | |
| 10-13 | 39 (22.2%) | 31 (32.0%) | 8 (10.1%) |
| 14-15 | 75 (42.6%) | 35 (36.1%) | 40 (50.6%) |
| 16-18 | 62 (35.2%) | 31 (32.0%) | 31 (39.2%) |
| Gender | | | |
| Male | 97 (55.1%) | 56 (57.7%) | 41 (51.9%) |
| Aetiology of Intellectual Disability | | | |
| Down syndrome | 26 (14.8%) | 21 (21.7%) | 5 (6.3%) |
| Other known cause | 58 (33.0%) | 37 (38.1%) | 21 (26.6%) |
| Unknown cause | 92 (52.3%) | 39 (40.2%) | 53 (67.1%) |
| Carer's highest level of education¹ | | | |
| Diploma; bachelor degree; graduate diploma or certificate, or a postgraduate degree | 41 (23.6%) | 30 (31.6%) | 11 (13.9%) |
| None of these above | 133 (76.4%) | 65 (68.4%) | 68 (86.1%) |
| Location ranked by level of socio-economic advantage | | | |
| Low | 56 (31.8%) | 21 (21.7%) | 35 (44.3%) |
| Medium | 73 (41.5%) | 43 (44.3%) | 30 (38.0%) |
| High | 47 (26.7%) | 33 (34.0%) | 14 (17.7%) |
| General health status ranked by carers | | | |
| Very good/excellent | 111 (63.1%) | 61 (62.9%) | 50 (63.3%) |
| Fair/good | 63 (35.8%) | 34 (35.1%) | 29 (36.7%) |
| Poor | 2 (1.1%) | 2 (2.1%) | 0 (0.0%) |
| Known health conditions reported by carers² | | | |
| Having at least one chronic physical or psychiatric condition known by carers | 120 (68.6%) | 70 (72.2%) | 50 (64.1%) |
| Having at least one chronic physical condition known by carers | 118 (67.4%) | 69 (71.1%) | 49 (62.8%) |
| Epilepsy | 32 (18.3%) | 23 (24.0%) | 9 (11.4%) |
| Heart condition | 18 (10.2%) | 12 (12.4%) | 6 (7.6%) |
| Psychiatric condition | 8 (4.6%) | 4 (4.1%) | 4 (5.1%) |
| Thyroid problems | 5 (2.8%) | 2 (2.1%) | 3 (3.8%) |
| Reflux oesophagitis | 9 (5.1%) | 6 (6.3%) | 3 (3.8%) |
| Aspiration | 4 (2.3%) | 3 (3.1%) | 1 (1.3%) |

¹ Missing information for 2 participants

² Number of "don't know" responses for known health conditions reported by carers: having at least one chronic physical or psychiatric condition known by carers: 1 (in special education units), having at least one chronic physical condition known by carers: 1 (in special education units), epilepsy: 1 (1 in special education schools), heart condition: 0, psychiatric condition: 0, thyroid problems: 0, reflux oesophagitis: 1 (1 in special education schools), aspiration: 0

Table S2. Responses for selected behaviour problems for participants who completed baseline questionnaires (n = 592).

| Behaviour problems ¹ | Total (n, %) | | | Special education school (n, %) | | | Special education unit in mainstream school (n, %) | | |
|--|-----------------|----------------------------------|-------------------------------|------------------------------------|----------------------------------|-------------------------------|---|----------------------------------|-------------------------------|
| | Not true | Somewhat or sometimes true | Very true or often true | Not true | Somewhat or sometimes true | Very true or often true | Not true | Somewhat or sometimes true | Very true or often true |
| Become over-excited | 145 (24.9%) | 212 (36.4%) | 225 (38.7%) | 57 (18.0%) | 114 (36.1%) | 145 (45.9%) | 88 (33.1%) | 98 (36.8%) | 80 (30.1%) |
| Stubborn, disobedient or uncooperative | 156 (26.7%) | 276 (47.2%) | 153 (26.2%) | 79 (25.0%) | 145 (45.9%) | 92 (29.1%) | 77 (28.6%) | 131 (48.7%) | 61 (22.7%) |
| Upset and distressed over small changes in routine or environment | 184 (31.4%) | 194 (33.1%) | 208 (35.5%) | 78 (24.7%) | 108 (34.2%) | 130 (41.1%) | 106 (39.3%) | 86 (31.9%) | 78 (28.9%) |
| Tense, anxious, worried | 183 (31.6%) | 260 (44.8%) | 137 (23.6%) | 103 (32.9%) | 127 (40.6%) | 83 (26.5%) | 80 (30.0%) | 133 (49.8%) | 54 (20.2%) |
| Preoccupied with only one or two particular interests | 193 (34.2%) | 128 (22.7%) | 244 (43.2%) | 85 (27.5%) | 69 (22.3%) | 155 (50.2%) | 108 (42.2%) | 59 (23.1%) | 89 (34.8%) |
| Kicks, hits others | 286 (48.9%) | 182 (31.1%) | 117 (20.0%) | 140 (44.3%) | 103 (32.6%) | 73 (23.1%) | 146 (54.3%) | 79 (29.4%) | 44 (16.4%) |
| Wanders aimlessly | 400 (68.5%) | 118 (20.2%) | 66 (11.3%) | 202 (63.7%) | 68 (21.5%) | 47 (14.8%) | 198 (74.2%) | 50 (18.7%) | 19 (7.1%) |
| Refuses to go to school, activity centre or workplace | 399 (68.7%) | 146 (25.1%) | 36 (6.2%) | 227 (72.3%) | 69 (22.0%) | 18 (5.7%) | 172 (64.4%) | 77 (28.8%) | 18 (6.7%) |
| Has nightmare, night terrors or walks in sleep | 404 (70.1%) | 117 (20.3%) | 55 (9.6%) | 214 (68.8%) | 63 (20.3%) | 34 (10.9%) | 190 (71.7%) | 54 (20.38%) | 21 (7.9%) |
| Inappropriate sexual activity with another | 489 (84.3%) | 59 (10.2%) | 32 (5.5%) | 257 (81.9%) | 36 (11.5%) | 21 (6.7%) | 232 (87.2%) | 23 (8.7%) | 11 (4.1%) |
| Sees, hears something which is not there | 507 (87.0%) | 49 (8.4%) | 27 (4.6%) | 273 (87.2%) | 23 (7.4%) | 17 (5.4%) | 234 (86.7%) | 26 (9.6%) | 10 (3.7%) |

¹ Behaviour problems were reported during the past 6 months.

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