Author: Gameren-Oosterom, Helma van
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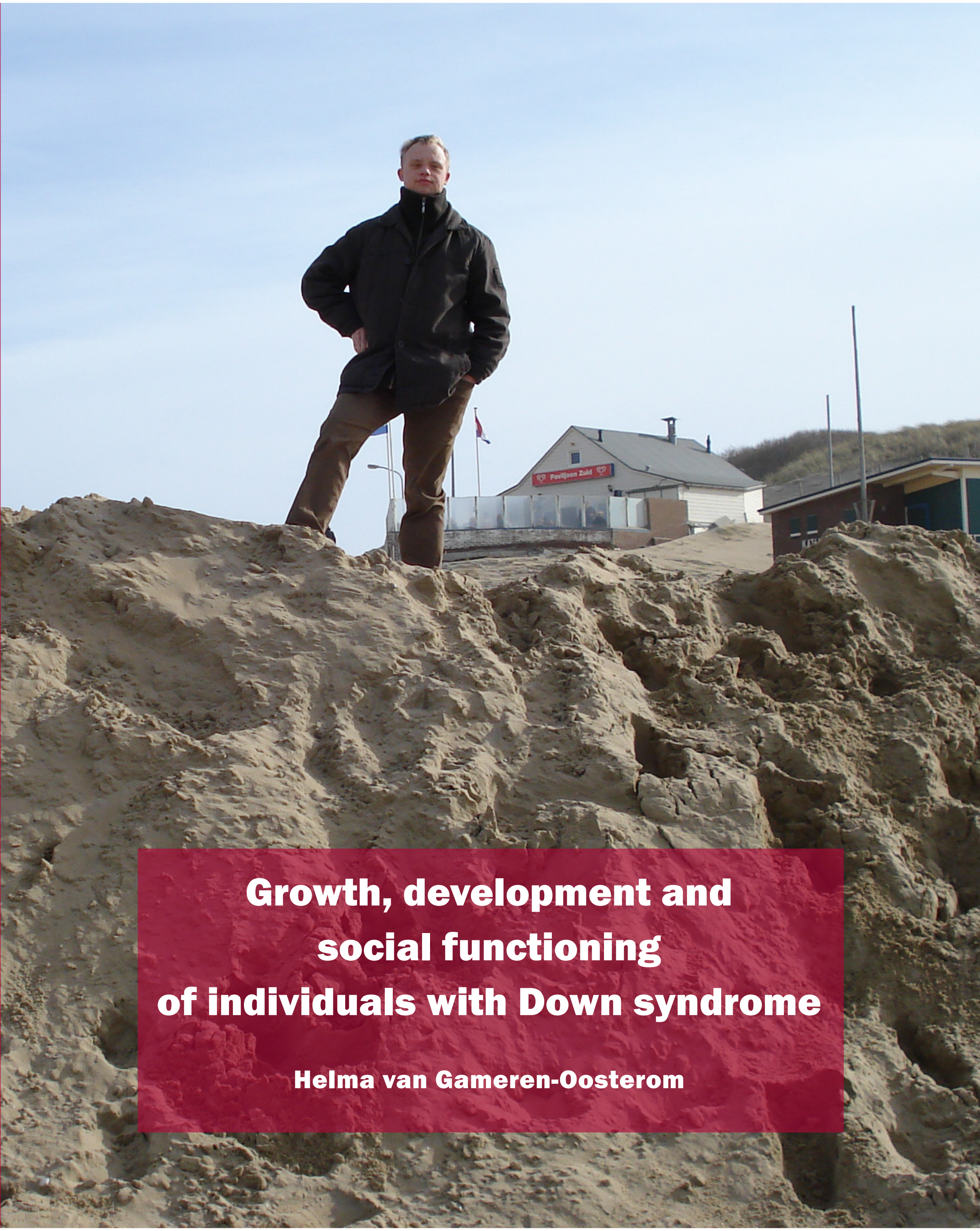

Growth, development and social functioning of individuals with Down syndrome

Helma van Gameren-Oosterom

Practical and social skills of 16-19-year-olds with Down syndrome: independence still far away

Authors
Helma B.M. van Gameren-Oosterom, MD
Minne Fekkes, PhD
S.A. (Menno) Reijneveld, MD, PhD
Anne Marie Oudesluys-Murphy, MB, PhD
Paul H. Verkerk, MD, PhD
Jacobus P. van Wouwe, MD, PhD
Simone E. Buitendijk, MD, MPH, PhD

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Abstract

Objective: Survival of children with Down syndrome (DS) has improved considerable, but evidence lacks on their current level of daily functioning upon entering adulthood. We therefore aimed to assess the degree to which adolescents with DS master various practical and social skills.

Patients and Methods: Cross-sectional data of a Dutch nationwide cohort of DS adolescents aged 16-19 year were collected using a written questionnaire for parents. This contains the Dutch Social competence rating scale and the Children's Social Behavior Questionnaire (CSBQ), to measure practical and social skills, respectively. CSBQ outcomes were compared to norm data from adolescents without DS. Data were available from 322 adolescents (response 62.8%).

Results: Up to 60% of adolescents with DS mastered some of the skills required for independent functioning, such as maintaining adequate standards of personal hygiene, preparing breakfast and being able to spend at least 30 minutes at home alone. Less than 10% had basic skills such as some cooking and paying in a shop. No participants managed to master all the skills necessary to be able to live independently. Most adolescents with DS (90%) had more problems with social interaction than others of the same age, especially on the areas of orientation and understanding social information. Boys with DS mastered less practical and social skills than girls with DS.

Conclusions: Adolescents and young adults with DS have limited practical and social skills that are needed for independent daily functioning. They remain dependent on parents and peers and other sources of support.

Highlights

- Adolescents with Down syndrome remain largely dependent
- They have serious difficulties in practical and social functioning
- Most adolescents master skills such as personal hygiene and answering a telephone
- Only a small minority can perform relatively more complex tasks
- None master all the complex skills needed to be able to live independently

Introduction

While growing up, becoming independent is a normal prospect for every young person and it also holds true for people with Down syndrome (DS). For the latter group becoming independent does not happen as naturally as for people without DS, because of their delayed cognitive and motor development caused by Trisomy 21. Prevalence of DS is estimated to be 12 per 10,000 live births in the United States[1] and 14.6 per 10,000 live births in the Netherlands.[2] Care has improved for people with DS during the past two decades and life expectancy has increased considerably. Currently, most (>80%) people with DS reach adulthood and their median age at death has increased, e.g. in the USA from 25 years in 1983 to 49 years in 1997.[3-5]

However, evidence lacks on the effect of the improved care for people with DS on their independent practical and social functioning. Learning of skills is usually stimulated intensively in children with DS from a young age onwards, e.g. by using early intervention programs, training social skills and additional attention at school age. It remains unclear, however, to what extend young people with DS really attain the skills needed for independent living in adulthood.

Current evidence on practical and social functioning concentrates mostly on skills during infancy and childhood, showing a delay in all DS children, but with considerable variability.[6-8] Evidence on general development and social functioning in adolescence and young adulthood is limited. Carr and Melyn were among the first to describe detailed observations on general development and intelligence quotient (IQ) of adolescents and adults with DS.[9,10] They found that adults with DS have gained only a small number of basic life skills. Especially, Carr observed that mean developmental scores for the girls were significantly higher than those for the boys, and those for the home-reared children were significantly above those for the non-home-reared.[10] Some other studies provide further information on the level of functioning and cognitive development, however, all subjects in these studies were born in the 1960s, 1970s and 1980s, before improvements in family and community attitudes and in health care practices.[11-15] The children born in those periods grew up in quite different circumstances and less stimulating environments compared to the generation born after 1990, the era when interventions to stimulate development have been implemented widely. More recently, the level of functioning of adolescents or young adults with DS is not extensively studied among large cohorts. Research on adolescents with DS born after 1990 has usually included only small numbers (<50) or focus on one specific area of development and cognition, such as reading skills or working memory.[16-20] Therefore, the aim of our present study was to assess the practical and social skills that adolescents with DS currently attain, overall and by gender.

Methods

We obtained data at ages 16-19 years on a Dutch nationwide cohort of DS children born in 1992, 1993 and 1994. The families of 513 children were invited to participate by letter from the Dutch Down Syndrome Foundation (SDS, parent organization). The SDS has contact with 86% of all estimated living 595 adolescents of this birth cohort in the Netherlands, based on an 81% survival rate.[2,4] The only selection criterion for inviting parents was the year of birth of the DS child. Reminders were sent after 4 and 8 weeks. Parents were allowed up to 4 months to reply after receiving the invitation.

Participating parents filled in a paper questionnaire concerning their child with DS. This included questions on practical daily skills, social skills and background characteristics. Written informed consent was obtained from parents/next of kin of all participants.

Practical skills

Practical skills first concerned competences according to the Dutch Social competence rating scale (SRZ). The SRZ measures practical and social skills specifically in intellectually disabled children aged 4 years or older. Its validity and reliability regarding practical daily skills in children and adults with DS has been reported to be good.[21,22] The SRZ contains 31 items on the level of mastering skills at four levels (ascending from less to better mastery of a specific skill). Table 7.2 summarizes all items, whereby for each item one of the four options described on the rating scale (mostly the highest level) is presented. The items can be grouped into four subscales: Daily living skills (skills for grooming oneself), Language use (making oneself understood), Task orientation (bear some responsibility, perseverance and taking initiative) and Social orientation (interaction with others). In our sample, internal consistencies of the subscales were good; they were: $\alpha=0.96$ for the total score, $\alpha=0.92$ for Daily living skills, $\alpha=0.95$ for Language use, $\alpha=0.84$ for Task orientation and $\alpha=0.72$ for Social orientation.

Additionally, practical skills were measured using a self-designed questionnaire on practical skills not covered by the SRZ. These items were selected based on semi-structured interviews with 25 parents of adolescents with DS (Table 7.3). The SRZ-items combined with these added items provide a complete view of the skills needed for independent daily functioning. The additional items could be rated as ‘does not apply’ (score 0), ‘applies’ sometimes or somewhat (score 1), or ‘applies usually’ (score 2).

All practical skills as measured are basic skills and adolescents (without DS) are generally considered to have all of these skills. No normative data on these items were available. However, it is possible to make an assessment because of the elementary nature of these skills.

Social skills

The mastering of social skills was investigated using the Children's Social Behavior Questionnaire (CSBQ), which measures a wide range of problems in various domains of development and social functioning.[23-25] The CSBQ has been shown to be a valid and reliable tool to assess the degree and pattern of social deficits in children with intellectual disability.[26] Normative data are available in the test manual.[25] For each of the 49 items, parents were asked to indicate whether the behavior during the preceding two months 'does not apply' for their child (score 0), 'applies sometimes or somewhat' (score 1), or 'applies clearly or often' (score 2). The items cover six subscales: Tuned (behavior/emotions not optimally tuned to the social situation), Contact (reduced contact and social interest), Understanding (difficulties in understanding social information), Orientation (orientation problems in time, place or activity), Stereotyped (stereotyped behavior and restricted activities or interests), and Changes (fear of and resistance to changes). The subscales have a good internal consistency in our sample: $\alpha=0.93$ for the total score, $\alpha=0.82$ for Tuned, $\alpha=0.88$ for Contact, $\alpha=0.82$ for Understanding, $\alpha=0.85$ for Orientation, $\alpha=0.81$ for Stereotyped and $\alpha=0.79$ for Changes.

Statistical Analysis

General characteristics of the study population were analyzed and differences between boys and girls evaluated using *t*-tests for continuous variables and chi-square tests for categorical variables. Next, we determined the proportions of the adolescents with DS who mastered the specific skills for all items of the SRZ and self-designed questionnaire. In addition, problems in social functioning (items of CSBQ) were determined for the adolescents with DS and compared to normative data from the general population, as available in the test manual, using *t*-tests. Effect sizes were estimated by dividing the differences in mean scores between the subgroups by the pooled standard deviation (SD). Cohen's effect sizes (d) were used for interpretation of relevant differences: $d<0.2$ is considered a negligible difference, $0.2<d<0.5$ a small, $0.5<d<0.8$ a moderate, $0.8<d<1.3$ a large and $d>1.3$ a very large difference.[27] Furthermore, differences between boys and girls were tested using *t*-tests. For all analyses, statistical tests were 2-tailed and statistical significance was defined at $p<0.05$. The analyses were performed using Statistical Package for the Social Sciences, version 17.0 for Windows (SPSS Inc, Chicago, Illinois).

Table 7.1: *Characteristics of adolescents with Down syndrome studied (n=322), data as reported by their parents; overall and by gender*

	Total		**Boys**		**Girls**		
General characteristics	**n**	**%**	**n**	**%**	**n**	**%**	***p****
Number of subjects	322	*100.0*	170	*52.8*	152	*47.2*	.000
Dutch descent^	300	*93.2*	162	*95.3*	138	*90.8*	.110
Age in years (range)	16.8 – 19.9		16.9 – 19.9		16.8 – 19.8		
Age in years (mean ± SD)	18.32 ± 0.82		18.34 ± 0.82		18.29 ± 0.82		.553
Living at home	283	*87.9*	149	*87.6*	134	*88.2*	.888
Early stimulation program participation	265	*82.3*	143	*84.1*	122	*80.3*	.366
Education attended at 16 years (n=319)							
Mainstream secondary school	23	7,2	8	4,8	15	10,0	.075
Special school	276	86,5	142	84,5	134	88,7	.271
None	20	6,3	18	10,7	2	1,3	.001
Ever enrolled in mainstream primary school	237	73.6	108	63.5	129	84.9	.000
≥3 years enrolled in mainstream primary school	193	59.9	82	48.2	111	73.0	.000

Abbreviation: SD – standard deviation, GA – gestational age
*Boys with Down syndrome compared to girls with Down syndrome
^ Both parents born in the Netherlands

Table 7.2: *Proportion of adolescents with Down syndrome (n=321; aged 16-19 years), who have the practical skills as measured by the Dutch Social competence rating scale (SRZ).*

Subscales	**% having the skill**
Daily living skills	
Dresses oneself completely, including footwear	59.8
Ties shoe laces	40.2
Takes (almost) always initiative to dress	78.2
Undresses oneself and changes into night attire	81.6
Washing hands and face properly without supervision	60.0
Brushes teeth with appropriate use of toothpaste	53.6
Uses adequate toilet hygiene	61.1
Makes up the bed with new sheets and pillowcases	24.5
Uses knife and fork at lunch and dinner	81.0
Uses a knife properly at dinner, including cutting meat (without bone) by themselves	69.8
Sets the table properly (plates, cutlery, napkins, food, etc.)	61.7
Cleans up after diner, empties plates and prepares for washing up	44.2

Language use	
Is able to pick up items without list (for example at the neighbors), when one or two items are requested	57.4
Uses more compound sentences when speaking, combining more events or remarks in one sentence	29.0
Pronunciation is generally correct and clear	12.1
Speech and language can be understood by most others	44.2
Reports full name and address	63.6
Repeats full sentences expressed by others	43.6
Uses full sentences to express own wishes	53.0
When asked a question, he/she answers with complete sentences	40.2
Tells a story while being aware of a situation, e.g., in a picture (indicating what has happened, or what is going to happen)	35.6
Task orientation	
Initiates clearing up (almost) always	36.1
Finishes tasks without being reminded (almost) always	32.7
Can maintain attention at a task when it lasts for more than 15 minutes, without being encouraged in the meantime	39.3
(Almost) always tidies up toys and other things, without being told to do so	24.9
(Almost) always hangs clothes, without being told to do so	24.0
Social orientation	
Shares (almost) always toys and tools with friends or family	24.1
Asks (almost) always permission to use items belonging to others	39.9
Plays usually by himself/herself	56.4
Often, or (almost) always offers to help others, without being told to do so, if others are incapable	33.0
Walks several streets away from home without supervision	34.0

Results

A total of 322 questionnaires were filled in completely (response of 62.8%). Two cases were excluded because of severe physical handicaps, extensively limiting daily functioning, which are not typical for DS. General characteristics of our sample are presented in Table 7.1. Mean age was 18.3 years (SD=0.82, range 16.8-19.9 years). All may be classified as late-adolescents (further denoted as ‘adolescents’), 52.8% were boys and 93.2% were of Dutch origin (both parents born in the Netherlands). Most adolescents lived at home (88%). The vast majority (82%) had participated in an early intervention program at home (such as the translated and adapted version of the Macquarie/Portage Programs). The majority had attended mainstream education for some years (74% had ever been enrolled in mainstream primary school). At the age of 16 years, only 7% were still enrolled in mainstream education and 87% attended special education.

Practical skills

Practical skills are presented in Table 7.2 and 7.3. Table 7.2, which shows all items of the SRZ questionnaire, and shows the proportion of adolescents who usually perform the activities in daily life. Most adolescents mastered certain skills required for independent functioning, e.g. 81% were able to use a knife and fork at lunch and dinner and 82% could undress themselves. About 60% were able to groom themselves, performing tasks such as getting dressed, and/or thoroughly washing hands and face, and/or using adequate toilet hygiene. Clear communication was difficult for most adolescents with DS and 44% can be understood by most other people, 29% only by people they know and 20% only by close caregivers. Nine per cent of adolescents were (almost) unable to speak at all.

Table 7.3 shows the additional list of practical skills. Some practical skills were mastered by most adolescents, e.g. 71% could manage to use a computer and television and 84% were able to swim. However, almost all adolescents experienced serious problems in performing practical tasks. About 55 to 60% of adolescents were able to prepare and eat breakfast and/or serve themselves a drink without assistance. Only a small proportion was able to cook a basic meal without assistance (7%) or was able to pay in a shop (12%).

Most parents could not leave their adolescent with DS at home alone for a longer period. Two thirds of adolescents with DS were able to spend at least 30 minutes alone at home, but one third of adolescents needed intensive supervision 24 hours per day. In traffic, 50% were able to cycle with supervision, but only 19% could cycle along a familiar route without supervision.

Social skills

With regard to social skills, the standard scores of the CSBQ showed that the majority (90%) of adolescents with DS experienced more problems in social functioning than adolescents without DS of the same age: 6.9% had a score just above average, 32.5% had a high score and 50.8% a very high score (the higher the score the greater the problems). A small percentage of adolescents had average (7.6%) or somewhat lower than average (2.5%) problem scores on social functioning. Scale scores of the CSBQ are presented in Table 7.4. In comparison to boys and girls without DS, total problem scores were much higher for boys and girls with DS, with very large effect sizes (1.69 and 1.50, respectively). The largest effect sizes were found in the subscales Orientation and Understanding.

Regarding interaction, 29% made little eye contact and 68% 'lived in a world of his/her own'. Most adolescents had some trouble processing information (67%) and understanding conversations (75%). With regard to mood, 33% angered easily and 43% had mood swings without apparent reason. Problems were also noted with compliance: 33% were regularly disobedient and/or could not be corrected. Half of the adolescents found changes difficult, e.g. they panicked easily, stayed passive in new situations and/or resisted change.

Table 7.3: *Proportion of adolescents with Down syndrome (n=322; aged 16-19 years) who have (usually) the specific skills (additional list)*

	% having the skill
Able to prepare and eat breakfast independently	55.5
Serves themselves a drink (without being supervised)	59.8
Able to perform basic cooking (like preparing a simple hot meal), without supervision	6.6
Able to spend 30 minutes alone at home	63.4
Able to spend a few hours alone at home	34.3
Use a key to enter a house, when nobody else is home	37.4
Needs care 24/7	39.2
Takes care to be in time at a standard appointment (e.g. ‘dinner at 6 o’clock’)	12.1
Uses (without assistance) the computer and television	71.2
Answers the phone properly	54.4
Phones other people independently	32.9
Understands a simple command (e.g. ‘get your coat’)	95.6
Expresses personal dislikes	77.5
Speaks in full sentence	56.1
Asks for help when in a difficult situation	45.0
Speech and language is only understood by close caregivers	19,9
Communicates by sign language and use of pictograms	13.1
(Nearly) unable to speak	8.7
Able to write short memos or emails (with some words)	43.3
Able to write notes and emails with some phrases	29.0
Able to read and understand short texts in magazines or books	41.7
Able to add numbers up to 10	43.6
Realizes that 8 is higher than 4	50.9
Knows the value of money (notes and coins)	9.4
Able to pay with cash in a shop	12.1
Able to pay with a debit card in a shop	8.7
Able to swim	83.9
Able to use a normal bike	40.5
Able to walk along the street near the home without supervision	49.9
Able to cycle in traffic under supervision	50.3
Able to walk along a familiar route without supervision	38.5
Able to cycle along a familiar route without supervision	18.8
Able to find the way to a familiar address (club or friend) without supervision	18.0
Able to take a bus ride (public transport) to a familiar place such as school, independently	5.9

Table 7.4: *Social skills of adolescents with Down syndrome (n=317; aged 16-19 years), measured by the Children's Social Behavior Questionnaire; by gender and compared to the normative sample (n=400). Higher scores denote more problems in social functoning.*

	Boys			**Girls**		
	Down syndrome (n=165)	**Norm (n=200)**		**Down syndrome (n=152)**	**Norm (n=200)**	
	Scale score			**Scale score**		
	Mean ± SD	**Mean ± SD**	**Effect size[1]**	**Mean ± SD**	**Mean ± SD**	**Effect size[1]**
Tuned[a]	5.11 ± 3.67	2.70 ± 3.37	0.69***	4.63 ± 4.09	3.42 ± 3.55	0.32**
Contact[b]	6.18 ± 5.54	2.32 ± 3.16	0.88***	6.02 ± 4.68	1.60 ± 2.53	1.22***
Orientation[c]	6.48 ± 4.04	1.12 ± 1.78	1.78***	4.88 ± 3.67	0.90 ± 1.59	1.48***
Understanding[d]	6.78 ± 3.66	1.71 ± 2.06	1.75***	6.89 ± 3.12	2.06 ± 2.24	1.82***
Stereotyped[e]	3.41 ± 3.58	0.58 ± 1.06	1.12***	2.22 ± 2.88	0.48 ± 1.08	0.85***
Changes[f]	1.96 ± 1.64	0.42 ± 1.02	1.16***	1.66 ± 1.56	0.41 ± 0.90	1.02***
CSBQ total[g]	29.93 ± 15.21	8.83 ± 9.62	1.69***	26.32 ± 14.38	8.86 ± 8.99	1.50***

* p<0.05, ** p<0.01, *** p<0.001

[1] Cohen's d effect size: d<0.2 negligible; 0.2≤d<0.5 small; 0.5≤d<0.8 moderate; 0.8≤d<1.3 large; d≥1.3 very large

[a] Tuned = 'not optimally tuned to the social situation'
[b] Contact = 'reduced contact and social interest'
[c] Orientation = 'orientation problems in time, place or activity'
[d] Understanding = 'difficulties in understanding social information'
[e] Stereotyped = 'stereotyped behavior and restricted activities or interests'
[f] Changes = 'fear of and resistance to changes'
[g] CSBQ total = CSBQ total problem score

Abbreviation: SD – standard deviation

Gender differences

Boys with DS mastered less skills than girls with DS (mean total score of SRZ: 86.6 vs. 96.4; p<0.001). Also on the subscales Daily living skills, Language use and Task orientation, boys with DS scored lower than girls (p-values <0.001, <0.001 and 0.004, respectively). The subscale Social orientation was the only one in which no gender difference was observed. Boys with DS had more problems than girls with DS in social functioning on the total CSBQ score (p=0.031), and the subscales Orientation (p<0.001) and Stereotyped (p=0.001); effect sizes ranged from 0.2 to 0.4, indicating an additional small effect of gender.

Discussion

In the present study we measured a wide spectrum of practical and social skills in a nationwide cohort of 322 Dutch adolescent with DS in the age range of 16.8-19.9 years. This cohort includes many individuals who have participated in early intervention programs and who often attended at least some years of mainstream education. The important issue is whether they have developed the necessary skills to be able to live independently as adults.

Our results show that most adolescents with DS master some of the skills required for independent functioning. About 60% of adolescents were able to maintain adequate personal hygiene unaided, and/or prepare and eat breakfast and serve themselves a drink without assistance, and/or spend a half hour alone at home, and/or can walk about the streets in the vicinity of the home without supervision. However, many basic practical and social skills were not mastered by them.

Carr has presented a comparable view of the level of practical and social functioning of young people with DS who were born in the 1960s, based on three cohorts.[11] She found that in general, about two-thirds of young people with DS are rated as independent in their feeding and toileting, one-third to two-thirds in dressing, about half in washing and bathing and about a quarter in hair washing. The present generation of young people with DS seems to have a roughly equal level of functioning in practical skills. However, it is difficult to compare Carr's data with our study data, because of the differences in selection of the study population and questioning. It may be that those basic life skills, measured by Carr, are the skills that parents in general try to teach their child and therefore resemble the current results of our present study. However, these days, intervention programs and care givers also try to teach children with DS basic math, reading and writing skills. It is not possible to compare specific skills, but it seems to appear that improved functioning of people with DS over the years is restricted to specific areas.

We also found that adolescents with DS had serious difficulties with social skills. Regarding the CSBQ, they scored substantially more problems on all domains of social functioning in comparison to the normative sample of peers without DS, especially on the areas of orientation and understanding social information. Studies in general samples of adolescents with intellectual disabilities reported similar findings.[28] Reports on levels of social functioning of adolescents with DS have not been previously published.

Our findings on social skills of adolescents with DS imply that they experience difficulties in dealing with others, in adapting to new situations and/or unfamiliar environments. They thus probably function better when living and working with support from familiar caregivers who know the best way to approach and stimulate them. For parents of a child with DS this has major implications. It means that the need for parental care for children with DS does not diminish when they enter adulthood. Their limited skills will hamper them from participating in activities and will limit their social engagement in activities outside the home, as shown by Wuang.[29]

Each additional specific skill that an adolescent with DS masters will have a major positive influence on daily life in their family. The extent of achieved practical and social skills affects the intensity of support needed. If an adolescent with DS is able to spend a few hours at home alone, parents will be able to leave them without always needing to arrange a replacing caretaker. If an adolescent is able to find the way to a familiar address without supervision parents do not continuously need to accompany him or her. The ability to use the telephone independently makes it possible for the adolescent to ask for help when experiencing a problem that he or she cannot solve when alone, which in turn may prevent panicking.

Our study has considerable strengths as it measured a wide spectrum of practical and social skills in a large nationwide cohort of adolescents with DS. However, some potential limitations should be noted. Firstly, although the participants were not selected from a specific activity or school, as in other studies, selection bias can still be present.[29] Parents with a more positive attitude towards their child may be more inclined to join the parent organization, conversely it is possible that those parents with relatively more problems with their child are those who may seek support by joining a parent organization. In our sample a relatively high proportion of parents have high education (55% vs. 33% in the general population).[30] This may mean that the rather low skills of the DS children in our sample are still an underestimation of the problems all DS adolescents meet.

Secondly, all results were based on parental reports. Parents may be tempted to emphasize positive aspects of the functioning of their child, rather than the negative. For example, in our study 36% of the parents indicated that their child was able to tell the time, however, only 12% were able to be home at a standard appointment (e.g. dinner at 6 o'clock). Again this implies that our study still underestimates the problems DS adolescents meet.

Overall, this study shows that all adolescents with DS have limited skills to perform the relatively more complex tasks needed for independent practical and social functioning. This leads to dependency on others. Therefore, adolescents and young adults with DS will always need intensive supervision and support, despite of the increased stimulation of development, increased opportunities to participate and increased acceptance in society.

The findings of this study stress the importance of teaching specific practical skills to children and adolescents with DS. Improvement in social skills, which subsequently influences the intensity of care needed, is of vital importance. Moreover, it is crucial for parents as well as for care providers to have realistic expectations regarding the level of independent practical and social functioning that a child may reach. First, professionals need to have appropriate information so they are well equipped to inform parents with a (newborn) child with DS. Parents need realistic information concerning DS, including an up to date overview of the possibilities of people with DS in present day society.[31] That should include information on the extremely limited chances for people with DS to become completely independent as adults, as shown in our study.

Further research is needed to develop intervention programs to specifically improve the skills of children with DS and to study their effectiveness. Numerous parent-directed and child-led interventions are currently available. However, it is not clear which, if any, of these approaches could be adapted for use in children with DS. The gap between our research findings and evidence-based interventions and effective educational approaches needs to be bridged. Furthermore, more insight is necessary into the social cognition of children with DS that they develop throughout childhood and on factors contributing to better daily functioning of these children.

Conclusions

We investigated a wide spectrum of practical and social skills in a unique, large nationwide cohort of Dutch adolescents with DS, assessed at 16.8-19.9 years of age. Our results show that adolescents and young adults with DS have limited practical and social skills that are needed for independent daily functioning. They remain dependent on parents and peers and other sources of support. For example fewer than 10% of the adolescents studied can cook a basic meal and pay in a shop. Only 44% can be understood by most people and one third cannot spend any time at home alone. The specific skills mastered by an adolescent with DS have effects on the degree of independence they can achieve and in turn highly affect the intensity of the support they need in later life.

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