

Observations on Nutrition and Weight Development in Children with Downs Syndrome

Introduction

Children and young people with Downs Syndrome and their parents are faced with a multitude of health-related problems. This frequently involves one particular topic, nutrition, being viewed from a professional rather than a parental point of view, which can lead to substantial long-term health problems and risks.

The weight gain in children with Downs Syndrome below the age of 3 is less than satisfactory or moderate at best. A multitude of reasons are given for this, for example:

- The raised incidence of cardiac abnormalities in DS children, especially the increasingly common av canal.
- Abnormalities and deformities of the gastro-intestinal tract, e.g. Hirschsprung's disease, pancreas anulare
- Orofacial dysfunctions
- Muscular hypotonia

This problem means that the feeding and nutrition for these children is often done in a way that includes, for example, more meals, energy-supplemented nutrition, or even formula feeding and a special diet. This leads more than a few patients and their parents to fixate on nutrition as a problem that everyday life must revolve around.

A large number of test subjects show a BMI progression that crosses the percentiles after the age of 3. Possible causes for this include:

- Maintenance of a higher-calorie diet, e.g. including following reconstructive surgery
- Resolution of orofacial problems and the related disruption of feeding and drinking
- Insufficient exercise
- Development of undesirable nutritional behavior with a preference for certain foods or food groups

These weight and activity problems worsen as children grow older, and possible causes for this include:

- Parental influence over the child decreases
- Facilities including special schools, residential schools, workshops, residential communities etc. do not focus enough on nutrition, nutritional behavior and exercise

Own Data

This retrospective study covers a group of 25 children with Downs Syndrome, 12 females and 13 males. We have been seeing these children on an advisory basis once or twice a year since they were 1, as part of our surgeries focusing on Downs Syndrome.

We have not noted a general increase in BMI of this kind in children and young people who we see regularly, and by that I mean at least once every 3 months. This may be because nutrition and exercise is a central theme of every consultation.

The following data is included:

- Anthropometric data, height, weight, and BMI
- Food plans over 3–7 days (specified precisely in grams) that are evaluated by a computer-aided nutritional analysis program (PRODI 5)
- An investigation of the activity index calculated as an average value over 4 weeks
- A laboratory check (clinical) at the time of the relevant consultation
- An exercise protocol over 4 weeks*

Activity Index (AI)*

We found it necessary to define an activity index (AI) ourselves, as we could not find a suitable method in the sports-medicine related literature available to us or on enquiry at the relevant facilities.

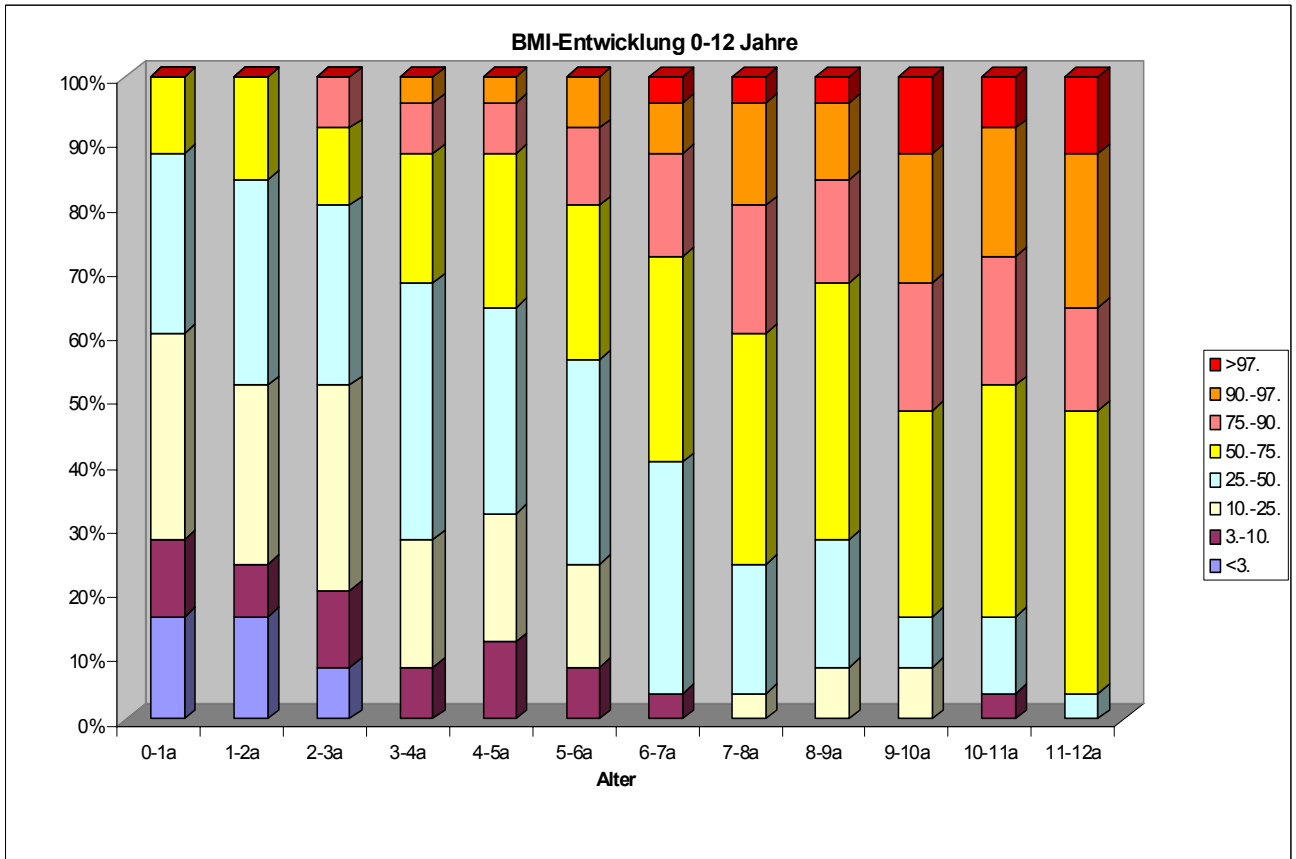
Our activity index (AI) is defined on the one hand by the number of weekly units, and on the other by the actual time. Only units under and over 30 minutes are included.

AI-4	4+ units/week	> 30 minutes/unit
AI-3	2–4 units/week	> 30 minutes/unit
AI-2	2–4 units/week	< 30 minutes/unit
AI-1	<2 units/week	>> 30 minutes/unit
AI-0	<1 unit/week	>>>30 minutes/unit

Results

1. There is no significant difference between females and males.
2. BMI progression over the age of 12

The graphic representation shows the BMI progression in % of the percentile.



3. Nutritional profile

A nutritional protocol over 3–7 days based on recommendations by the German Nutrition Society (Deutsche Gesellschaft fuer Ernaehrung—DGE) is drawn up during the consultation at the age of 12. This includes values specified in grams. The protocols are analyzed by a computer evaluation program (Prodi 5.0/5.1) and the results are compared with the DGE recommendations and the D-A-CH (German Accreditation Body for Chemistry) reference values 2000 for that age group.

Energy input and macro foods

BMI	<25th perc. (0 subjects)	25-75th perc. (12 subjects)	>75th perc. (13 subjects)
Energy input	-	98.5% (92-104%)	112% (96-132%)
Protein	-	18.5% (16-22%)	18.2% (15-22.5%)
CH	-	55% (45-62%)	57.5% (43-67.5%)
Fats	-	18% (15-22%)	26.5% (13-32%)

-of which animal fats	-	36% (32-45%)	48% (35-72%)
-of which plant fats	-	64% (55-68%)	52% (28-65%)

Selected micro foods

BMI	<25th perc. (0 subjects)	25-75th perc. (12 subjects)	>75th perc. (13 subjects)
Iod	-	86% (54-101%)	75% (45-93%)
Selen	-	54% (34-75%)	52% (31-80%)
Biotin	-	85% (56-110%)	56% (32-91%)
Vitamin A	-	75% (43-125%)	68% (48-112%)
Vitamin E	-	82% (67-109%)	73% (56-101%)

4. Laboratory values

The following values (selected) are determined by routine blood tests (clinical) for all subjects during the consultation at the age of 12:

BMI	<25th perc. (0 subjects)	25-75th perc. (12 subjects)	>75th perc. (13 subjects)
Homocystein<9	-	10.5 (7.0-16.5)	14.2 (8.5-21)
Cholesterine<200	-	172 (125-215)	187 (132-265)
HDL>35	-	38 (23-76)	35 (28-65)
LDL<155	-	98 (76-164)	158 (145-189)
Selen 53-105	-	63 (32-68)	61 (28-71)
Biotin >200	-	165 (110-450)	142 (<100-250)

5. Activity index

An exercise protocol averaged over 4 weeks produced the following activity index:

	BMI <25th perc. (0 subjects)	BMI 25-75th perc. (12 subjects)	BMI>75th perc. (13 subjects)
AI-4	-	3	0
AI-3	-	4	1
AI-2	-	4	2
AI-1	-	1	3
AI-0	-	0	7

Discussion and Summary

The nutritional pattern and problems of children and young people with Downs Syndrome requires close inspection, analysis and, if necessary, early intervention. The first priority should be diet problems involving difficulties with drinking and eating, frequently in connection with moderate or even poor growth levels in young patients. This often also correlates with a range of additional functional disorders such as cardiac and gastro-intestinal abnormalities or orofacial dysfunctions, but also with disruption to the interaction between mother and child. This problem can also resolve itself during infancy, however, in that the quantity of food intake is no longer an issue, but this still frequently results in an inadequate intake of energy. This leads in turn to a BMI that rises steadily as the years go by.

Parents have to be alerted to this problem, and ongoing training is necessary. The advice that we provide during our annual consultations with these patients has not proved to be effective enough. Close monitoring and professional advice that focuses on weight progression and nutritional patterns appears to be necessary. Facilities that look after children and young people with Downs Syndrome also need to focus on this problem.

The nutritional pattern is also the result of a learning process, which means it can be modified and corrected. It is therefore important to aim for the best standard of nutrition possible, particularly from the point of view of preventing nutrition-related illnesses. Generally recognized nutritional concepts such as those from the DGE can be used as guidelines for this. Children and young people with Downs Syndrome should also be encouraged to participate in sporting activities. Downs Syndrome in itself does not exclude sporting activities, although attention should of course be paid to specific problems such as cardiac genesis. Endurance sports like walking and cycling etc. are ideal, with around 3 sessions of at least 30 minutes every week. Encouraging young people with Downs Syndrome, who tend to prefer more passive leisure pursuits, to take part in sporting activity like this requires a high level of motivation from their caregivers.

We have been collecting data on nutritional patterns in people with Downs Syndrome since June 2004. You are most welcome to help with collecting this data. More information is available on our home page at www.kinderarzt-bretten.de

Dr. Matthias J. Gelb
Specialist in Pediatric and Adolescent Medicine
Specialist in Nutritional Medicine for the DGE
Member Scientific board TRISOMY 21 Research
gelb@kinderarzt-bretten.de