### Description:
This quality of life in chronic disease tool was developed concurrently by researchers from seven European countries (Austria, France, United Kingdom, Netherlands, Sweden, Greece and Germany), all following the same steps. In addition to the generic module, there are seven disease-specific modules, one of which is epilepsy.

The DISABKIDS chronic generic module (DCGM-37) has three domains, each including two dimensions for a total of 37 items: physical domain including a limitations dimension (6 items) and a treatment dimension (6 items), mental domain including an independence dimension (6 items), and an emotion dimension (7 items), and social domain including an inclusion dimension (6 items), and an exclusion dimension (6 items). All items are scored on a Likert scale of 1 to 5 (1=excellent or problem is never, 5=poor or problem is always).

Scores are averages of the total scores for a dimension. The dimension can be scored if there is no more than one item missing for the dimension. The total health related quality of life is the sum of all dimensions scores rescaled (and transposed) to 0-100, with 100 being the highest quality of life.

The instrument has been validated for use in the following languages: English, French, German, Dutch, Greek, and Swedish. All forms of the instrument appear in all these languages.

It is usable for children between the ages of 8 to 16 years. There is a proxy version.

There is a short version with only 12 questions, covering the same domains, which should be used more for screening purposes.

There is a DISABKIDS Smiley form for children 4-7 years old or children who have not reached reading ability. It takes approximately 5 minutes to complete.

The epilepsy module has been developed as a supplement to the chronic generic module and includes two scales – Impact, which includes anxiety about having seizures and the potential public stigma (5 items) and Social which assesses self-esteem and comparison to others (5 items), in both child and parent versions for the 8-16 year olds and a proxy/parent version for the 4-7 year olds.

### Particular Features:
The instrument can be done either by paper or using a computer program called RUNQUEST with very minimal computer hardware requirements. The DISABKIDS is copyrighted and is available for a cost.

### Psychometric Properties:
Internal consistency reliabilities (Cronbach’s alpha) between 0.70-0.87 and test-retest reliability (ICC: 0.71-0.83). Discriminant validity was shown by girls showing lower quality of life than boys on the physical and emotional domains, adolescents showing lower emotional scores than younger children, family affluence is associated with higher quality of life in all domains and dimensions as is a higher score on the Clinical Global Impression scale. Internal consistency values on the epilepsy scale are α =0.90 for the Impact scale, and 0.83 for the Social scale.

Sensitivity to Change: Not tested.
Relationships to other variables: DISABKIDS were related to the International Classification of Functioning, Disability and Health (ICF) scales and showed differences and similarities between generic and condition-specific DISABKIDS modules.

Strengths and Weaknesses:
Strengths: The chronic generic module can be used in conjunction with any of the condition specific modules including the epilepsy module. It has a wide age range. It is available to use internationally because of the concurrent development process in several countries.
Weaknesses: Not used or validated in the US. Copyrighted.

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The DISABKIDS group holds the copyright for all DISABKIDS Core Instruments and DISABKIDS Disease Modules. There may be fees for usage.

References:


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Fava L, Muehlan H, Bullinger M. Linking the DISABKIDS modules for health-related quality of life assessment with the International Classification of Functioning, Disability and Health (ICF). *Disability Rehabilitation.* 2009; [Epub ahead of print].