

Educational consequences of rare conditions – development of an observation instrument

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Background

Knowledge of educational consequences of rare conditions, and of how to adapt the treatment, environment and activities to create the best possible conditions for participation and learning, is often lacking. Many professionals also report lack of sources of knowledge. Knowledge formation and dissemination are thus of utmost importance.

Aim

In order to aid knowledge formation and dissemination Ågrenska has developed a broad observation instrument for children with rare diagnoses, identifying both abilities and difficulties on a group level.

Method

The instrument consists of 144 quantitative and 71 qualitative items and covers ten areas: social/communicative ability, emotions and behaviours, communication and language, ability to manage his/her disability and everyday life, activities of daily life, gross and fine motor skills, perception and worldview, prerequisites for learning and basic school abilities.

Up till now we have gathered data for 540 children with 35 different rare diagnoses.

Validity and reliability

The instrument was content validated against a number of existing instruments. The items were considered relevant as they, with few exceptions, appear in well-known assessment tools.

Interrater reliability was calculated for the quantitative items usually observed during the course. Interrater reliability reached 92,5%.

Preliminary analyses using Cronbach's alpha as well as multinomial logistic regression indicate that the proposed observation instrument is useful for identifying complex diagnosis-specific features that lead to specific every day and pedagogical consequences.

Conclusions

The observation instrument seems to be useful for identifying complex diagnosis-specific features that lead to specific every day and pedagogical consequences, how consequences vary within each diagnosis, and how functional impairments affect school and everyday situations.

