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INTEGRATED PREVENTIVE CARE FOR CHILDREN WITH DOWN'S SYNDROME IN THE NETHERLANDS: ANALYSIS OF THE ACTUAL DATA

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The exact data of incidence at birth, mean duration of the pregnancy, perinatal morbidity and mortality are unknown for children born with Down syndrome (DS). The vast spectrum of accompanying disorders (eg. congenital heart disease, gastrointestinal disorders) as well as feeding- and psychomotor problems hampers parents in their proper care. They feel a need to structure health care visits resulting in care of their DS child that is integrated and is managed optimal. The Paediatric Association of the Netherlands developed in collaboration with the Dutch DS parent organisation in 1998 a Down syndrome preventive checklist. This checklist describes specific advises for care of the DS. In order to plan necessary care and its capacity, DS is by 2003 part of the DPSU (Dutch Paediatric Surveillance Unit).

We present the questionnaire that follows every case of DS to the DPSU and give preliminary data for new-born children with DS born in the Netherlands in 2003.

Birthweight distribution, duration of the pregnancies, perinatal morbidity, care problems as well as social factors are part of the questionnaire, but also an inventarisation of the different paramedical support started after birth is included.

Conclusion: In 2003 DS is part of the DPSU which gives data about care and health problems around and after birth of a child born with DS.

