Defining clinically relevant quality indicators that matter to people with Down syndrome

19th International Conference on Integrated Care, San Sebastian, 01-03 April 2019

Francine van den Driessen Mareeuw1,2, Antonia Coppus3,4, Diana Delnoij5,6, Esther de Vries1,2

1: Tilburg University, Tilburg, The Netherlands; 2: Jeroen Bosch Hospital, ’s-Hertogenbosch, The Netherlands; 3: Radboud University Medical Center, Nijmegen, The Netherlands; 4: Dichterbij, Center for the Intellectually Disabled, Gennep, The Netherlands; 5: Erasmus School of Health Policy and Management, Rotterdam, The Netherlands; 6: National Health Care Institute, Diemen, The Netherlands

Introduction: Down syndrome (DS) is related to many comorbidities. People with DS need lifelong (DS-specialised) healthcare provided by many different professionals. Little is known about the quality of available healthcare. This impedes monitoring, improvement and transparency. We aim to develop quality indicators (QIs) providing insight into quality of DS-healthcare.

Methods: Semi-structured interviews were held with people with DS, with parents, and focus groups with support staff working at service providers for people with intellectual disabilities. Thematic analysis yielded issues important to people with DS regarding healthcare and well-being. Healthcare professionals participated in a Delphi study in which they commented on statements based on the interview/focus group outcomes. All perspectives were assembled in a preliminary set of QIs.

Results: According to people with DS, parents, and support staff, healthcare quality is related to: Collaboration of involved professionals, including those outside healthcare (e.g. school, daily activity centres); Accessibility of suitable healthcare (nearby and ‘findable’); The right balance between burden and outcome of a treatment; and Good communication between healthcare professionals and people with DS (+ carers). Although most healthcare professionals agreed these issues are important, their priorities were more clinically oriented (e.g. less focused on involving the social network around their clients with DS, considering health screenings as (more) important determinant of healthcare quality). There was no consensus about whether the QI-set should provide information on provider, departmental, or organisational level and to whom quality information should be accessible.

Discussion: To our knowledge, we are the first to develop QIs for DS-healthcare and one of the first developing QIs together with both patients and providers. Some considerations came across. QIs should: 1) Function as framework for high quality DS-healthcare, while leaving room for personalising care; 2) Provide insight into possibilities for improvement, reflecting the right balance between complexity of DS-healthcare (as results show) and clear and concise QIs (for usability),
“only a few QIs should measure as much healthcare quality as possible”; 3) Provide people with DS (+ carers) with sufficient information to choose the best suitable healthcare (i.e. transparency).

**Conclusion**: Involvement of people with DS and their carers as well as healthcare professionals has proven to be crucial in identifying QIs that are clinically relevant and add value to the lives of people with DS. The preliminary QI-set includes insights from both 'sides', around four main items: Medical processes (e.g. screening, adherence to guidelines); Organization of healthcare (e.g. integrated care); Interaction between healthcare professionals and their clients with DS (+ carers); Contribution to well-being (e.g. burden-outcome balance of treatment).

**Lessons learned**: Involving both people with DS (+carers) and healthcare professionals is challenging, but necessary for developing relevant and usable QIs. This study not only results in QIs but also in insight into best practices in DS-healthcare.

**Limitations**: The study only included people with DS who were able to participate in an interview. Parents may have decided to participate because they were very (dis)satisfied about healthcare quality.

**Suggestion for further research**: Investigate best ways to implement the QIs, together with all stakeholders.

---

**Keywords**: quality indicators; measures; patient participation; down syndrome; qualitative research; delphi study