

Supplemental File 1 - Delphi Interview

Interview Topic Guide

This interview is concerned with the following topics

(1) Can you begin by explaining what, in your expert opinion, are the goals of care / the principles that should govern care when a child has a life-limiting neurodevelopmental disability?

- Explain why each goal is important / relevant in the care of this population.

(2) In your opinion how do current services meet those goals?

- Which goals are achieved and which are not?
- If goals are not achieved in the context of current services why do you think this is so?

(3) What changes are necessary to current services to improve the care of children with life-limiting developmental disabilities and their families?

- What is required in order to achieve these changes?