

Additional File 3: Example Questions from the Interview Guide used in the INSPIRE parent study (translated from German) (Esser et al., 2022)

Overview of everyday life
• Can you tell me about the support you receive for your care, health and day-to-day needs during an ordinary week?
Questions about the current care situation
• Can you tell me what works well in your current care situation? • Can you tell me who you contact when you have questions about your current care situation or health?
Needs assessment
• Can you tell me if anyone has ever looked at your situation as a whole with you and considered what kind of support you need?
Coordination and communication
• Is there someone who, in your opinion, keeps an eye on and manages your care as a whole?