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Quality of life in young autistic children: where do we stand?

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What is quality of life, and how can we assess it?

Quality of life is a very broad concept, influenced by physical and mental health, level of independence, social relations and relationships to important elements in one's environment. Quality of life is therefore multidimensional and includes objective indicators, namely the person's environment, as well as subjective aspects, or what the person perceives. We use quality of life measurement tools to characterize well-being, with the goal of then improving it. Using these tools, researchers and public officials can collaborate in order to positively influence quality of life.

How does quality of life fit in to health research?

Ultimately, quality of life is the most important measure when assessing whether a health intervention is effective. In autism, quality of life is increasingly emphasized in the assessment of pharmacological and psychosocial interventions.


Why is it important to consider an intervention's impact on quality of life in young autistic children?

Most early interventions offered to families are assessed by their impact on signs of autism. However, more and more researchers now think that an effective intervention should improve the quality of life of the children receiving these interventions, and not simply be based on its capacity to modify a behavior.

Why?

1. This is what parents and autistic people want
2. We have good reason to believe that autistic children have lower quality of life than their typically developing peers
3. Current interventions have not proved that they can significantly modify signs of autism
4. The number of different early interventions has increased considerable over the past 10 years. We know very little about their possible side effects. However, these early years are crucial for determining current and future well-being in many children.
5. Pediatric research highlights the importance of taking children's' opinions and experiences into account. Quality of life measures include a subjective component, which integrates their perspective.

Evaluating quality of life in young autistic children: research priorities

Very little work has been done measuring the impact of early intervention on the quality of life of autistic children. The few studies which do look into this use measurement tools validated in typically developing children. Due to functional differences in autistic people, these tools cannot reliably assess quality of life in these children. Researchers suggest designing specific quality of life measurement tools, using participatory methods which involve autistic people at every step of the process. This will not be without its own challenges, as language and communication difficulties in young autistic children make it difficult to solicit their opinion. 

Main references:

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