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Quality of life in autistic adults:

searching for what really matters

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Almost all research suggests that autistic adults face significant difficulties in their day-to-day lives, that they struggle with access to autonomous living and healthcare services, and that they may face unemployment and suffer from physical and mental health issues. Despite these findings, we still know relatively little about how to help autistic adults to better reach their full potential. One of the reasons for this is the current lack of agreement on which criteria to use in evaluating the effects of an intervention. For example: is it important for an autistic person to have a lot of friends? Would they rather prioritise a well-paid job, or professional opportunities related to their interests? These questions are extremely complex to address given the amount of heterogeneity encountered across the autistic spectrum. Over the last decade, researchers have begun to take a serious look at this issue, in order to address the needs of three different groups: parents advocating for the

rights of their adult children, autistic adults who have come out in large numbers to express their needs, and professionals who do not always manage to identify these needs and appropriately respond to them.

Quality of life in autistic people is a burgeoning field of research, and is considered particularly important by autistic people and their families. However, though increasingly recognised as an important construct, research on quality of life faces at least 3 major obstacles:

- 1 Researchers do not agree on how to define quality of life! The only consensus researchers have more or less reached is that it is a multidimensional, subjective concept, as described by the WHO's definition: quality of life is "an individual's perception of their individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and

Main references:

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McConachie, H., Mason, D., Parr, J.R., Garland, D., Wilson, C. & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, 48(5), 1596-1611.

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concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."

- 2 Suppose we manage to agree on a suitable definition of quality of life. The next logical question would be how to assess it: how do we measure quality of life in an individual? This concept does not describe a precise, specific and observable phenomenon, all of which are necessary to develop a "valid" measurement tool using a scientific approach.
- 3 Quality of life measurements in autistic adults are probably different than for typically developing adults. Indeed, autistic people may attribute less value to certain conventional criteria, such as those pertaining to social activities, for which few autistic adults will reach high quality of life levels. It may therefore not be appropriate to use quality of life measures validated within the general population. Researchers have actually attempted to develop a quality of life measurement tool specifically for autistic adults, and this task demonstrated that their quality of life may not be as poor as we think.

However, the problem still remains: we do not have a clear understanding of which specific aspects are important to measure and linked to quality of life in autistic people. A first step would be to better identify

which aspects of quality of life matter most for autistic people and affect daily living. Once a consensus is reached on what constitutes "good" quality of life, we will then be able to seriously tackle the development of measurement tools. This consensus research cannot be conducted without the active participation of autistic people.

Collaborative approaches: the path to a solution

Centering the voices of autistic people is crucial for the purposes of, (1) producing research that autistic people identify with, and (2) better understanding their perspectives and experiences in order to develop relevant ways to improve their quality of life. In order to do this, we must increase their participation in research, and consider them important contributors to scientific knowledge. In practical terms, this approach involves collecting data directly from autistic people, in addition to data collected with families and the rest of the community (namely clinicians).

This trend towards collaborative approaches is increasingly found in research. A prime example of this is the Adults Autism Spectrum Cohort, a large-scale project initiated by an English research team. Amongst other projects, this group has developed and validated a module within a quality of life measure that is specific to autistic adults. 