

A framework for measuring and using Quality of Life data to improve outcomes for students with Autism and their families.

Introduction

Most of us will have an intuitive understanding of what constitutes a good quality of life but as a theoretical construct, Quality of life (QoL) is notoriously complex. It is difficult to define, to measure and to predict, particularly for those with lifelong conditions such as Autism (Tavernor et al., 2013). Yet, a good QoL is undoubtedly a highly desirable outcome for individuals with Autism and for their families (Cusack, 2017).

Recent studies have investigated QoL measurement and outcomes issues in life with Autism and some have considered the impact of Autism on family QoL (Vasilopoulou, 2016). One major issue has been identified by Tavernor (2013) as the lack of a condition-specific QoL measure for Autism – one that captures the essence and realities of daily life from an autistic perspective.

The call for a condition-specific measure of QoL in Autism has now been answered (Eapen, 2014) and in partnership with University College London's Centre for Research in Autism and Education (CRAE), Swalcliffe Park School participated in the recent validation of this instrument –the Quality of Life in Autism (QoLA) questionnaire.

Rationale

Swalcliffe Park is a specialist day and residential school for boys aged 10 to 19 with Autism Spectrum Conditions. For some time, the school has been supporting students to develop knowledge, attitudes and skills in four key domains: communication, independence, self-management and achievement. Now, students are using the QoLA as a means of systematically contributing to more meaningful targets for themselves. The QoLA allows them to voice judgements on how they are feeling about their autistic behaviours and their own QoL.

Family QoL data is also being collected via the QoLA with a view to determining the feasibility of tailoring specific support and guidance for each individual family. Parents provide information on how problematic they are finding their sons' autistic behaviours and how they are feeling about their own QoL.

Main points

This approach has led to the development of a whole school framework for linking QoL data to target setting for students and families.

Our presentation will describe Swalcliffe Park School's QoL framework for systematic data collection, evaluation and implementation. It will illustrate trends in individual and collective student progress over time from a QoL perspective. Quantitative and qualitative data from the QoLA will be presented to illustrate these trends. We will also consider issues arising from a comparison of student and family perspectives on QoL.

We will illustrate how the collective QoL data from students and their families has allowed the school to re-examine and re-conceptualise its service offer to both groups. Discussion will also include how we are currently working with partner schools to see how our Quality of Life framework might be replicated in different contexts.

References

Cusack, J. (2017). Participation and the gradual path to a better life for autistic people. *Autism* 21(2), 131-132.

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