

Developing a Quality-of-Life measure for autistic children in schools

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Introduction

With autism waiting lists increasing, services and their capacity are being impacted. This means that children with autistic symptoms and unmet needs are unable to get through to services to access the support they need.

Aims

1. To identify the proportion of autistic children who may remain unidentified and unsupported in Kent, Surrey, and Sussex (KSS).
2. To identify personalised areas of need for autistic children in KSS.
3. To develop a modified and locally adapted quality of life measure for CYP with autism to identify priorities for autistic children's self-care.

Objectives

- To answer the following research questions:
1. What proportion of autistic children in KSS remain undiagnosed?
 2. How can we improve the health and wellbeing of children with a broader autistic phenotype across KSS?
 3. What do autistic children in KSS report they want/need to help them live with issues they face on a daily basis?

What we've learnt so far

- Difference in autism prevalence in different countries from systematic review
- Current approaches in schools and building interest in schools from advisory group meeting

What has been achieved so far

- Systematic review abstract on autism prevalence submitted to conference
- Advisory group meeting and local YPAG meeting discussing study set-up and study materials
- Building community interest on SEND network

What has excited us

Working together across different systems and expertise: schools, experts in autism research and policy, and those with lived experience



Collaboration with advisory and local YPAG groups



Working with schools and school staff



Involving CYP throughout the study

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