

Effectiveness of Integrated Care Interventions on Mental Health Outcomes for Parents and Carers of Autistic Children in the UK: A Systematic Review

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1. Introduction/Rationale

Autism Spectrum Disorder is a neurodevelopmental disorder that is a lifelong condition which determines the way the individuals communicate, interact, and perceive the surrounding environment (National Autistic Society, 2024; NICE, 2021). The level of awareness in the United Kingdom has become significantly higher; it is approximated that there are about one million individuals with autism (NHS Digital, 2025; British Medical Association, 2023). This increasing awareness has burdened schools, health care services and community agencies with more complicated needs. To parents and carers, an autistic child means significant restructuring of the day-to-day role. To handle behavioural difficulties, families often exceed the use of traditional parenting, arrange more specialised therapies, and represent the needs of their children (Bonis, 2016; Hayes and Watson, 2013). This is a high-level of caring load, which comes with increased stress and anxiety and emotional burnout as opposed to regular developing children parents (McKenzie et al., 2021). The disjointed character of the support services in the UK is one of the contributors to this burden. Human services, social care, and healthcare are often run on different systems (The King's Fund, 2022). To most families, there may be complexity and lack of coordination when dealing with Child and Adolescent Mental Health Services (CAMHS), primary care, and social care. The result of this fragmentation is usually long wait times, frequent transfers, and inadequate information sharing among providers (Crane et al., 2023).

2. Prevalence

Autistic children constitute about 1 percent of the population in the UK (NHS Digital, 2025; O'Nions et al., 2023). Greater awareness has resulted in the growth of requirements in diagnostic and support services which puts a great burden on available systems. Consequently, it has led to a greater number of parents and carers being psychologically distressing, with studies always measuring an increased anxiety and depression rate (McKenzie et al., 2021). Research also indicates that the chronic fatigue experienced by caregivers is strongly correlated with the demands of taking care of autistic children in the long term (Bonis, 2016). Long queues in the process of assessing autism are added to these pressures in England, as the demand usually surpasses the services offered (NHS England, 2023). Finally, in such extended waiting bays, family members often have minimal guidance, which adds to emotional pressure and causes them to be left along uncertain care tracks (Crane et al., 2023).

3. Research Question

What is the effect of Integrated Care Interventions compared with usual non-integrated care, on the mental health outcomes of parents and carers of autistic children ?

4. Research Aim

- To evaluate the effectiveness of integrated care interventions in improving mental health outcomes for parents and carers of autistic children.

5. Research Objectives

- Identify evaluative studies of integrated care interventions for parents and carers of autistic children.
- Describe the intervention components and their level of integration (e.g., care coordination, key worker models, multidisciplinary pathways, or integrated family support programmes).
- Synthesize the effects on parents' mental health outcomes, specifically stress, anxiety, depression, and well-being, and report the outcome measures used.
- Assess the quality, risk of bias, and strength of evidence of the studies and identify which intervention components appear to be the most promising

6. Research Impact

The systematic review will present evidence on the effectiveness of integrated care interventions to the mental health outcomes of parents and carers of children with autism in UK. The results can guide policymakers and Integrated Care Systems (ICS) to enhance the provision of coordinated and multidisciplinary health and social care. Enhanced service integration can facilitate health and social care professionals to provide more efficient and family-focused care and reduce the stress that parents experience and enhance the support channels of families.

Autism Assessment Waiting Lists in England (2020-2025)

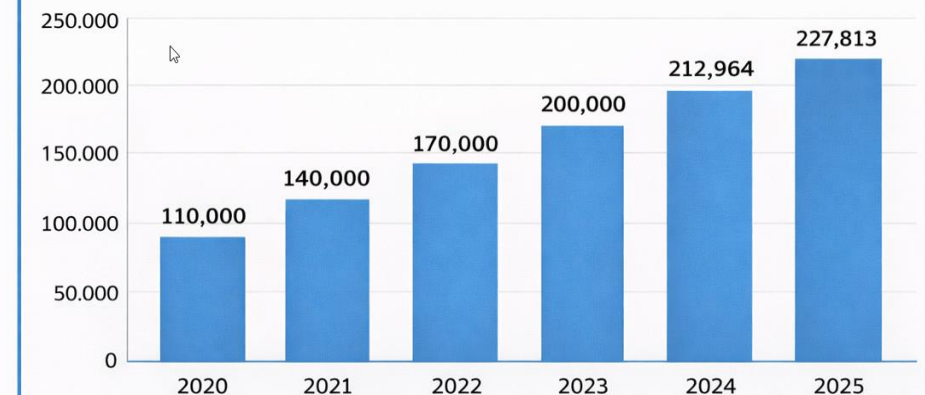


Figure 1: Increase in autism diagnostic waiting lists in England between 2020 and 2023, demonstrating rising demand for assessment and support services (NHS Digital, 2025; National Autistic Society, 2025), Aut4 et al., 2023).

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