

Blueprint for radical redesign of care for autistic children



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Some of the world's leading experts on autism have published a redesigned care pathway for autistic children and their families based on early detection and family involvement.

Published in *The Lancet Child and Adolescent Health*, the new pathway created by an international team aims to improve the organization of health and care services for [autistic people](#) in the UK and internationally.

"Existing services are reactive and often unevidenced, despite recent scientific advances in how to identify and support [autistic children](#) from their early years, public discussion and advocacy," said Professor Jonathan Green from The University of Manchester in UK.

"But we now have the evidence and ideas to enable us to re-design care for autistic children and families in a way that fits the 21st century."

Using 20 year's work in service development and the use of digital technology, the team argue an integrated early care pathway will improve the service autistic children and their families receive.

They draw on the best available quality evidence in autism, and ideas from what has worked in care for other enduring [health conditions](#) internationally. The approach involves identification of signs of neurodiversity in [early childhood](#) before diagnosis and links to [family](#)-based care.

It has been shown by the team in previous research to reduce some of the stress and difficulties an autistic child can experience during their development. And it can, they say, ease waiting list bottlenecks for later autism diagnosis and long waits for children and families before care.

Following diagnosis, similar models of family-based care give families the best tools and confidence to look after their child in ways that have been shown to improve the child's long-term development and well-being. The authors then propose an integrated system of supportive care

through Case Management and targeted additional ("step-up/step-down") targeted specialist intervention. This ongoing care system uses new digital health technologies and collaborative work with parents to provide them with appropriate long-term supports for the child's evolving needs.

Professor Green said: "Existing services are reactive and often unevidenced, despite recent scientific advances in how to identify and support autistic children from their early years, public discussion and advocacy. But we now have the evidence and ideas to enable us to re-design care for autistic children and families in a way that fits the 21st century. We have tried in this model to combine the best ideas from how services are organized for other health conditions internationally, the best evidence from our field on identification of neurodiversity and associated care, along with listening to what families and the autistic community say they need.

"We want to move from a system with long waiting lists which is often reactive to crises—to an integrated system that identifies needs earlier on and provides the appropriate early support that will provide enduring support and minimize later difficulties. Innovations in digital health technologies will be important in making such a system workable."

Autism spectrum conditions are a developmental aspect of neurodiversity affecting at least 1:100 people and often having a profound impact on children's social development and their and their families' wellbeing into adulthood.

"Digital health technologies provide an unprecedented opportunity to facilitate proactive and personalized care and support to autistic children and their families," says Professor Sandra Bucci, an NIHR Research Professor and Professor of Clinical Psychology at The University of Manchester and one of the authors; "This is already occurring in other mental [health](#) areas, and it is time to leverage digital tools to optimize care for children and their families and clinical workflows in services."

"Professor Josephine Barbaro, La Trobe University, Australia said "This proactive model of care from early identification to targeted supports is extremely timely, given recent evidence of highly effective early autism screening from 11 months of age."

"Too often we see autism therapies and supports untethered to any evidence," says Professor Andrew Whitehouse from the Telethon Kids Centre Perth Australia; "By contrast, this new pathway is deeply embedded in 20 years of clinical research, and holds great promise of connecting children to the evidence-based supports that they need. This is a vision that is ready for adoption."

Dr. Venkat Reddy, consultant neurodevelopmental pediatrician and lead clinician, Cambridgeshire and Peterborough NHS FT, Officer for Digital Health and Technology, UK Royal College of Pediatrics and Child Health says; "This integrated planned model of service delivery supported by digital technology has the potential to provide a blueprint for support and interventions for autistic children and their families across the world. This is extremely timely as we are all trying to develop long term strategies and action plans to achieve early recognition and needs led support for autistic [children](#)." -medicalexpress.com/news, March 16, 2022