An integrated early care pathway for autism

Jonathan Green, Kathy Leadbitter, John Ainsworth, Sandra Bucci

In this Viewpoint, we argue for the need to reconceptualise an integrated early-care provision for autistic children in the light of their enduring support needs and relevant new findings from developmental and intervention research. This model goes beyond short-term reactive care to outline an early proactive, evidenced, developmentally phased, and scalable programme of support for autistic children and their families from the earliest opportunity, with timely access to later step-up care when needed. We also integrate this model with emerging opportunities from data science and digital health technologies as a potential facilitator of such a pathway. Building on this work, we argue that the best current autism intervention evidence can be integrated with concepts and evidence gained in the management of other enduring health conditions to support an autistic child and their family through their early development. The aim is to improve those children's social communication abilities, expand their range and flexibility of interests, and mitigate any negative impacts of sensory difficulties and restricted, repetitive behaviours on the child and their family wellbeing. The pathway solutions described could also be adapted for older adolescents and adults and could be used within the health systems of different countries, including within low-income and middle-income contexts.

Introduction

Autism is a priority for health and care systems across the globe because of its prevalence, often poor outcomes, and enduring impact for individuals, families, and societies. Characteristics of autism relevant to this high impact include the lifespan-enduring nature of support needs for many and the loss of relative social independence, given current social provision. The current pattern of care provision internationally is patchy, reactive, usually received too late and short-term focused, and commonly not evidence-based.[1] Making an effective and efficient response poses challenges for health and care systems across the world. The enduring nature of the condition has not until recently been fully considered in care planning, despite the fact that much more is now known about the developmental trajectories of autistic children, the relative variability of trajectories before school attendance, and their greater stability later in development.[2] In this paper we use the identity-first language of autistic children rather than person-first language such as children with autism; acknowledging and respecting the different views on this usage within the autistic community and among professionals.

Evidenced models for managing long-term conditions in other areas of health care (eg, diabetes, depression, or hypertension in adults) have various common features that could be translated into provision for childhood autism. They emphasise three key factors. First, they foreground the central need for supporting patient self-care and resilience, implying a day-to-day ownership and involvement in the condition, supported by focused education, psychological, and systems support.[3] The family-focused interventions for autism described in this Viewpoint fulfill these criteria and are foundational for the new autism care pathway we propose. A second core factor of other evidenced models is the value of sustained clinical case management, which is key to the collaborative care model for mood disorders in adults[4] and part of the National Institute for Health and Care Excellence (NICE) recommendations for management of autistic children,

young people, and their families.[5] The third factor is the need for what can be termed a step-up and step-down: from the foundational intervention as above, into other specialist support and back again,[6] taking care that this is timely and only lasts as long as needed. In the proposed autism pathway, this movement between foundational and other specialst support is focused on the response to later-arising co-occurring conditions and associated problems.

For application to autistic children and young people, these features of other evidenced enduring care health models need to be understood in the context of the child's development and the family or carer support network around them.[7] Crucially, there is now well evidenced detection and intervention practice for autism that is consistent with these models; and these are at the heart of the care pathway model we propose for young children up to the age of 11 years (figure). Such an integrated sequence of detection and care could ideally be combined

Division of Neuroscience and Experimental Psychology, School of Biological Sciences (Prof J Green FRCPsych, K Leadbitter PhD)**, and Division of Imaging, Informatics and Data Sciences** (Prof J Ainsworth PhD) **and Division of Psychology and Mental Health** (Prof S Bucci ClinPsyD)**, School of Health Sciences, Faculty of Biology, Medicine, and Health, Manchester Academic Health Sciences Centre, University of Manchester; Department of Child and Adolescent Mental Health, Manchester Royal Children's Hospital** (Prof J Green)**; Complex Trauma and Resilience Research Unit, Greater Manchester Mental Health NHS Foundation Trust, Manchester, UK** (Prof S Bucci)

Correspondence to:
Prof Jonathan Green, Division of Neuroscience and Experimental Psychology, School of Biological Sciences, Faculty of Biology, Medicine, and Health, Manchester Academic Health Sciences Centre, University of Manchester, Manchester M13 9PL, UK
jonathan.green@manchester. ac.uk

Key messages

- Autism is an early-onset developmentally enduring condition, yet health system responses internationally have typically been reactive, poorly evidenced, and lacking a planned anticipatory or long-term care approach.
- Evidence from other enduring health conditions suggests the importance of supported self-care, evidenced universal foundational treatment, and ongoing case management, with timely step-up and step-down additional care when needed.
- The best emerging evidence from autism detection and intervention science now makes viable such an integrated and anticipatory detection and care pathway in autism, using a combination of early detection, pre-diagnostic and post-diagnostic family-focused interventions, and later step-up and step-down support.
- New digital health technologies could be a key part of the health-care system re-design that would be necessary to bring this about.
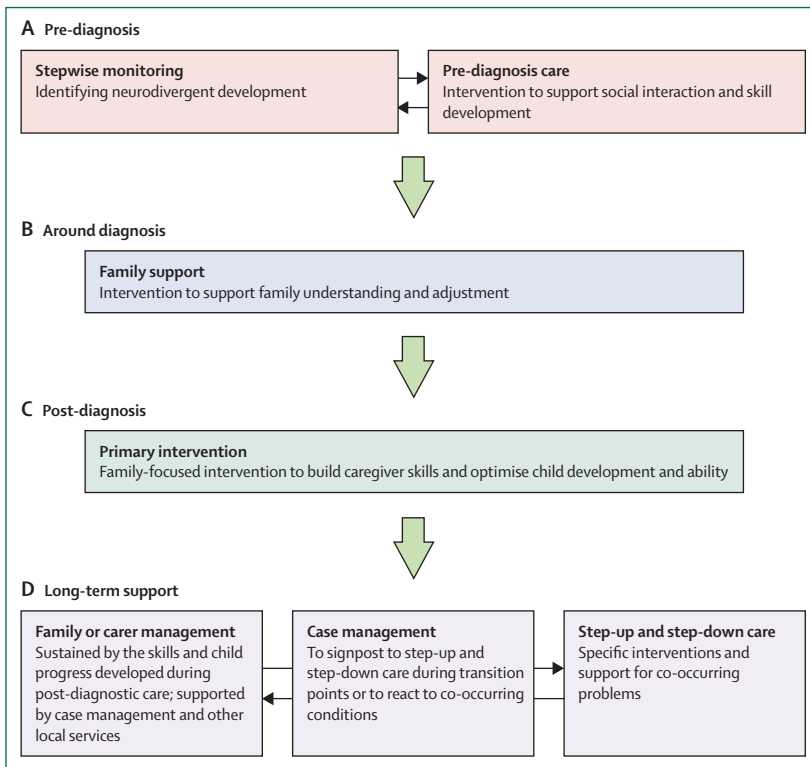
Figure: A developmentally phased care pathway for young autistic children (up to age 11 years)
Similar pathways could be prepared for autistic adolescents and adults.

Panel 1: The potential for new digital health technologies to support and enable the early autism care pathway

Pre-diagnosis: digital apps

- Digital apps could help parents track their child's development and share information with professionals, which could create improved efficiency of service response
- The resulting shared assessment could help reduce the diagnostic bottleneck in autism service response, and give a first step towards a co-owned health record

Post-diagnosis and long-term support: co-owned health records

- Co-owned health records could enable families of autistic children, and autistic adults later, to take ownership; they could use an integrated digital record to track changes in their wellbeing while self-managing and could request stepped up support if issues are escalating
- Professionals could use a system to actively case manage stepped up care for a patient across different services
- Aggregating data and analytics from integrated records could potentially build a learning health system in which it becomes possible to predict when a person's health or wellbeing is at risk

Family and individual self-management: apps, communities, and content

- Smartphone apps, managed online communities, and digital content could deliver low-intensity support on-demand; a suite of evidence-based resources could be immediately available for families of autistic children and autistic adults while self-managing

Case management: digital navigators

- Digital navigators (a person who is able to support both clinician and patient in real-time data streams using and implementing digital health technologies in clinical care) could show families of autistic children and autistic adults how to use co-owned health records and digital self-management content, and could help coordinate requests for stepped-up support through a digital case management system

sequentially over time, thus giving potential additive effects for a child's development and adaptation. The potential solutions described here are also conceptualised in a way that they can be adapted for use in adolescence and adulthood and within the health systems of different countries, including within low-income and middle-income contexts.[8]

Creating a feasible pathway of pre-diagnosis, post-diagnosis, and long-term support for autistic children will require significant work to redesign the provision of health and care services. Emerging opportunities from data science and digital health technologies could be a particularly effective and efficient means of delivering some of the service infrastructure required for providing feasible long-term support for autistic people (panel 1). Smartphones have great potential within the digital health infrastructure. They can capture longitudinal, dense, and multimodal physical and mental health data for use in diagnosis and monitoring. Smartphones can also analyse data using advanced statistical approaches or, more recently, machine learning, to generate clinically actionable insights and predictions, and they can widen access to treatment pathways such as digital health interventions delivered via apps, video conferencing, chatbots, or virtual reality.

From this data foundation, it could then be possible to build a learning health system[9,10] by aggregating data across the population and applying data analytics to develop predictive models and generate actionable insights. Data arising from these actions closes the feedback loop of the learning health system, driving new insights with additional data. Understanding how digital health technologies and complex digitally enhanced care pathways can be used and integrated into routine clinical practice requires meaningful partnership with all stakeholders. Documented priorities for the autism community include interventions to improve mental health and the development of communication skills and support for parents or carers to better understand and care for their autistic child.[11] Any element of service redesign must involve participatory methods and integrate stakeholder viewpoints and experiences.[12,13]

Pre-diagnosis: integrated detection and care

The developmental period before neurodivergence consolidates into a diagnosable autism phenotype can typically last for the first 2–3 years of life, but sometimes longer. There have long been calls from researchers within the neurodevelopmental science community[14,15] for pre-diagnostic (sometimes called pre-emptive) intervention efforts focusing on antecedent neurodevelopmental trajectories rather than reacting to the current, behaviourally defined, diagnostic symptom cluster. Two decades of prospective developmental research with infants at high familial likelihood of developing autism[16,17] have revolutionised understanding of these early years and suggested potential routes of intervention. In addition, developmental surveillance or monitoring from infancy is now more successful in identifying early behavioural signs of autistic traits with specificity and predictive validity.[18–21]

Relatedly, recent research on pre-diagnostic interventions for autism[22,23] includes several randomised controlled trials with substantive developmental follow-up of outcome effects over 18–24 months until 3 year diagnostic ascertainment. The results of these follow-up trials are particularly salient for a prospective developmental care pathway such as that advocated here. Within these trials, recruitment into a pre-diagnostic pathway has proved feasible from both a selective strategy of familial increased likelihood in the first year of life[24,25] and from community screening for autism-related concerns from age 12–14 months.[26–28] Various earlier trials[26,27,29–32] found inconsistent effects on parental interaction and no sustained effects on child developmental outcomes. Recently, a 5-month, home-based, parent-mediated intervention model (iBASIS-VIPP), which focuses on establishing early interaction synchrony between a potentially neurodivergent child and their caregiver, has been tested. Two trials identified and recruited infants at increased familial likelihood at age 9 months (n=54)[33] and community-identified concerns at 12 months (n=103);[34] both included long term follow-up in each case to 3-year diagnostic review. These two trials showed a replicated treatment effect to significantly reduce overall the degree of autism-related symptom behaviours during the intervention and through post-treatment follow-up to 3 years (appendix p 1). In addition, in the second trial, Whitehouse and colleagues[34] showed a reduced odds ratio of an infant having a clinical autism classification at 3 years (OR 0·18, 95% CI 0–0·68, p=0·02), representing a number needed to treat of 7·2 to reduce the odds of an autism classification, although these children remained developmentally atypical in other ways, for instance developmental dyspraxia or language difficulties.

The results from these two trials of the iBASIS-VIPP intervention demonstrate the first replicated and sustained effects of a pre-diagnostic intervention on later autism-related developmental trajectories. The categorical effect of reducing autism classification shown in the second trial[34] is consistent with these dimensional effects on autism related trajectories, but has not itself been shown previously and requires replication. These findings are relevant for the integrated care pathway proposed in this Viewpoint since they begin to fulfil the ambition noted earlier for care that is focused on helping early developmental trajectories rather than being reactive to phenotype diagnosis. The iBASIS-VIPP intervention is rooted in a transactional model of development,[35] concerning how children and contexts shape each other in development, as well as in basic developmental science studies, based on this model, of bidirectional social interactions between neurodiverse infants and caregivers and others.[36] On the level of developmental theory and science, such interventions would allow care to be organised around new understandings of the nature of neurodevelopment, and how abilities, functioning, and phenotypes emerge from neurodivergence and in transaction with environmental experience.[22] Such an early care pathway would also address the increasing presentation of families in the community with concerns around early infant social development.

These findings have, however, also engendered debate, with concerns from members of the autistic community and beyond, focused on two areas: first, that the intervention constitutes a behavioural modification that threatens to remove autism; and second, that success in reducing diagnostic classification might disenfranchise families from specific autism diagnosis-dependent support. In response, the authors of the iBASIS-VIPP studies and other commentators have made it clear[37,38] that the iBASIS-VIPP intervention is conceptually and practically quite different from earlier behavioural modification interventions such as applied behaviour analysis and some related developmental behavioural treatments. Rather than working with infants to modify their behaviour, iBASIS-VIPP works with parents to help them value, nurture, and adapt to neurodiversity and related social communication patterns in their baby, with the aim of producing an adapted synchronous environment for the infant. Subsequent developmental gains reflect the positive consequences of such infant experience, leading to increased developmental ability and reduced stress for the child, although some neurodivergence and associated needs remain.

The second concern relates to how support has historically been constructed around categorical diagnoses within many health systems. The findings in this Viewpoint arguably suggest a reframing of developmental thinking and support towards more dimensional (but still carefully defined) neurodiversity and associated needs.[39] That the clinical diagnostic construct could be somewhat malleable in early development has potentially substantive implications for developmental theory, but this can be considered as conceptually rather different to the idea of autistic social identity. Some of these issues are shared

with other early detection pathways in health; in autism, they will require ongoing engagement and conversation with families, autistic adults, and advocates, and such interaction is intrinsic to the spirit of this model.[22]

There are further substantive implications of these recent trials for health system thinking and resource allocation around neurodevelopmental conditions within the early years. At a service level, the results open up the prospect of a stepped integrated detection and care model that might mitigate the common diagnostic bottlenecks in services. These bottlenecks are partly caused by the current requirement for high-level, complex clinical classification assessments, which are sometimes but not always needed. Although diagnostic categorisation is currently prioritised for service triage, a focus on early trajectory pathways would refocus care more flexibly on assessed need within neurodiversity (a concomitant challenge would be to manage demand efficiently). For other children who fall below an autism threshold on surveillance but who have other developmental disabilities or cognitive delays, it will be important to offer equivalently appropriate and focused care support. The Portage programme for wider developmental difficulty or targeted language therapy programmes,[40] could be useful examples. At a resource allocation level, this will require a new focus on integrated training and implementation across early years services, such as community health (health visiting in the UK), child development, and child mental health at the service of evidenced proactive rather than reactive care. Embedding early autism detection within universal early years monitoring could also have the added value of reducing barriers to access to care in autism, documented for relatively marginalised and vulnerable populations within communities.[8]

Given the lack of an adequate developmental monitoring workforce (for example, health visitors) now in many geographical areas, digital health technologies could potentially be used to support parents to observe and interpret their child's behaviour and therefore aid autism identification, assessment, and support. Because parents are closest to their infant and most often the first to feel and report concerns about their development, apps are increasingly available to provide information on how to observe and interpret their infant's behaviour and record and share their findings with professionals within a developmental surveillance network. The ASDetect model is one evidence-based example with planned studies for field testing.[40] In this model, if early signs of autism at this initial parental-report stage are identified, then the child can be triaged for professional attention and the next stage of assessment in a stepped-care assessment model. This process could continue until a final step involving a clinical autism diagnosis. Such digital health technology solutions are in the early stages of piloting internationally, with pilot data indicating 84% positive predictive value between 11–30 months.[41]

Around diagnosis: family support and education

20–50% of parents of autistic children show clinically significant levels of mental health needs within the immediate post-diagnostic period and on an ongoing basis.[42,43] Current post-diagnostic provision is a source of substantial dissatisfaction to health-care professionals and parents.[44–47] There are long-standing initiatives to provide group-based psycho-education for parents as well as peer support, some of which have evidence of acceptability or observational evidence that is suggestive of positive outcomes.[47,48] In the past 5 years, there is increasing focus on interventions that support parents' emotional needs, including adjustment to the diagnosis, long-term stress management, resilience, and protection against stigma, using approaches such as mindfulness, cognitive restructuring, and acceptance and commitment therapy.[49–51] Such programmes are not yet formally evidenced for impact, but an ongoing, large-scale, UK trial is evaluating the effectiveness of a group-based, post-diagnostic programme that blends psycho-education and acceptance and commitment therapy to address the informational, relational, and mental health needs of parents. If shown to be effective, this programme would fill an evidence gap within current care pathways.

Post-diagnosis: core support for social and other development

Fundamental to the rationale for the proactive, anticipatory, and developmentally integrated care pathway described in this Viewpoint is evidence that intervention care can influence autistic and family development in predictable and sustained ways over time for relevant outcomes. In practice, however, clinical services in autism internationally are currently often poorly evidenced, patchy, and reactive in provision—a situation highlighted by recent intervention science reviews that include critique of the quality of the evidence.[1,52–55] Nevertheless, these same reviews do identify forms of family-focused, parent-mediated interventions during the early post-diagnosis period that give evidential support in a number of ways for the pathway model advocated in this Viewpoint. First, working with and through parents in this way is relatively low intensity for services compared with therapy delivered directly by a therapist to the child. It has the additional benefit of increasing parental empowerment and family resilience,[56] which is foundational for the family's self-management and resilience in providing ongoing care, as has been identified[3] as central to successful care in other enduring conditions.

Second, such family-focused, parent-mediated interventions have evidence from good quality studies for generalisation of treatment gains beyond the parent–child dyad and the strongest current evidence for longer-term developmental impacts after treatment end; relevant to this pathway model.[1,52–54] Specific social communication

intervention mediated through parents or teachers is the only 'consider' intervention recommendation in UK NICE guidance for core autistic development.[5] One of these social communication interventions relevant for this post-diagnostic phase of the pathway is the Paediatric Autism Communication Therapy (PACT),[57] a video-aided intervention for parents to improve their awareness of and responsiveness to their child's often complex communication. Replicated randomised trial evidence for clinic-delivered PACT[57,58] shows improvement in child autism-related symptom behaviours (ie, social communication ability, and extent of restricted, repetitive and sensory-related difficulties), over the course of intervention and after a 6-year follow-up period (effect size 0·55, 95% CI 0·14–0·91, p=0·004). The pattern of this long-term improvement in development closely echoes that found above in the conceptually analogous iBASIS-VIPP early years pre-diagnostic intervention already mentioned (appendix p 1). Evidence for PACT adapted to home and education is pending. A further social communication intervention developed in the USA, the Joint Attention Symbolic Play and Engagement and Regulation (JASPER) intervention,[59] has also shown positive developmental effects 2 years after the end of therapy, particularly on improving language outcomes and parent–child social engagement, although a 2021 systematic review of this model[60] suggested some caveats to its overall evidence base. Recent narrative and systematic reviews and meta-analyses[1,52–55] contain detailed review of the evidence for these and other potentially relevent intervention styles for this phase of the pathway.

Application of digital health technologies to facilitate the pathway

The idea of co-ownership of health records between families and health systems is well established in paediatric health care. The key to any co-production approach is a single integrated digital health-care record that brings together information known about the patient, which is accessible by those involved in their care. An integrated digital health-care system such as that summarised in panel 1 would facilitate communication and shared decision making with families, and would provide the foundation for coordinating a multi-agency approach.

Integrated digital health systems have already been trialled in other long-term conditions. For example, CFHealthHub[61] is a multifaceted system that supports people with cystic fibrosis and their clinical teams to develop their knowledge, skills, and self-efficacy (patient and clinician activation) and to build habits of self-care that create autonomy in prevention; this reduces effort and subjective burden while increasing adherence to self-care. EMPOWER[62] is a digital remote monitoring solution that uses a stepped care model to prevent relapse in schizophrenia. The EMPOWER intervention was co-designed to enable participants to monitor changes in their daily wellbeing using a mobile phone, blended with

peer support. Clinical triage of changes in wellbeing suggestive of early signs of relapse is enabled through an algorithm that triggers a check-in prompt, which in turn informs a relapse prevention pathway, if warranted. A peer support worker was involved in setting up and providing fortnightly follow-up for people using the app, fulfilling the role of digital navigator (panel 1).

The evidence behind the interventions in the pathway outlined in this Viewpoint comes from face-to-face delivery, and we assume this will remain the mainstay going forward. Nevertheless, there has been a great increase in recent years, accelerated by the COVID-19 pandemic, of remote technology delivery of intervention, which is likely to continue. This raises the question of whether the interpersonal remoteness that is consequent to using digital health technology in interventions might dilute or negatively affect therapeutic alliance or intervention effectiveness, or both. In fact, evidence from therapeutic alliance studies suggest that valid alliances can be made with digital applications and computers or phones, and that from the service user's perspective, the alliance can be comparable to face-to-face interactions.[63–65] Equivalence trials of remote versus face-to-face delivery of various specific mental health interventions, separate to autism, have generally suggested no difference in efficacy.[66,67] In autism specifically, various studies[68] report user satisfaction with telehealth delivery of established interventions, although a minority of families struggled due to technical challenges or relative digital poverty in the home (eg, availability of suitable technologies). However, measuring user satisfaction in this way is different to testing the comparative effectiveness of remote versus face-to-face interventions in practice, which needs to be a research priority going forward.

Collaborative production and care

The evolution of the kind of pathway model that we are proposing will increasingly include provision for co-production in service design[69] and collaborative care[70] in its operation. The latter encompasses three core principles: shared information (ie, health records), shared engagement (ie, decision making), and accountability (ie, replacing medical authority with mutual trust). The pathway and intervention model that we propose is consistent with these developments. Other areas, beyond the remit of this paper, in which co-design will be useful include the further elaboration of outcome measurements relevant to user needs. Work on the PACT intervention, for instance, included such development with the co-production of a user-nominated therapy outcome measure that showed improvement after treatment.[56]

Longer-term care: step-up support and case management

Into the school years, life for autistic children and their families can become stressful and complex, with

Attention deficit and hyperactivity disorder
- Stimulant medication management
- Family guidance

Anxiety
- Cognitive behavioural therapy[72]
- Anxiolytic medications

Mood disorders
- Adapted psychological therapy
- Medication management

Obsessive compulsive disorder
- Adapted behavioural intervention
- Cognitive behavioural therapy
- Medication management

Concerning or challenging behaviours for others*
- For example, irritability, resistance, or angry reactions
- Such presentations are often an expression of underlying anxiety, environmental distress, trauma, or physical pain, and they should not just be treated symptomatically
- Underlying remediable causes excluded, autism-adapted individual parent-training has good initial evidence for creating behavioural change,[73] and similar group-based programmes have some preliminary support[74]
- In severe cases, medication management with medications such as aripriprazole[75]

*We suggest the term "concerning behaviours". There is often understandable resistance from parents and others to disruptive or oppositional behaviour terminology in this context; it can be felt as stigmatising and can lead to the use of unvalidated terms such as pathological demand avoidance.

increasing vulnerability to mental health difficulties. Conceptualising this situation is helped by recognising that the social difficulties for an autistic child understanding their environment are often matched by those of their environment understanding the child. This has been characterised as the double empathy problem[71] and is consistent with the transactional approach within developmental science that underpins the early intervention part of this pathway[35] (ie, the relevant environments for very young children are interpersonal within the family, and extend to the wider social and physical environment as the child gets older). Presenting difficulties are often the result of autistic children being within a poorly adapted relational, educational, or physical environment, and equal attention therefore needs to be paid to adjustments within the environment and management at the individual, familial, and societal levels, as well as within-child factors. Detailed discussion of these wider adaptations, although key to the overall social and political response to autistic needs in the community, is beyond the remit of this health-focused Viewpoint. As part of individuation in development, many autistic children and adolescents will increasingly set their own treatment goals in collaboration with families and health-care professionals. These goals might

appropriately differ from those established with families in early childhood.

Key to the rationale of the anticipatory, developmentally focused pathway outlined in this Viewpoint is that its timely implementation will increase early adaptation and resilience in both child and family. Along with appropriate adjustments from social environments and education and a decrease in social stigma, this should decrease subsequent mental health difficulties and needs. Where difficulties remain, however, there will be a need for management within autism-aware generic mental health services, or to a step-up care provision from autism-specialist teams using evidenced practice. For emerging co-occurring problems, previously NICE[5] recommended the use of specific interventions that already have an evidence base for neurotypical children, with appropriate adaptations for autism; this is now inadequate advice going forward. The aetiology and management of co-occurring mental health difficulties is often different in neurodivergent versus neurotypical children, and more specific aetiological research and intervention development for the autistic context is necessary. A detailed review of interventions for co-occurring conditions among autistic people is beyond the scope of this review but is summarised in recent publications[21] and panel 2.

Digital health technologies for long-term monitoring

One important function of a shared health-care digital infrastructure would be to provide early warning of substantial decompensation or deterioration in symptoms or development, prompting consideration for timely step-up specialist care. A range of tools and health-care apps are currently available to support this monitoring function. However, with only around 2% of such technologies supported by any original research evidence[76] widespread clinical application will need to come with caveats at this time, prior to further study.

Case management

Ongoing clinical case management aims to provide support to sustain family self-care and resilience[3] and be an interface between family support and multi-agency collaborative care between health, social care, and education. The implementation of ongoing case management would reflect a health-care system designed around autistic people's evolving support needs, rather than one reactive to the tyranny of the urgent.[77] But how practical is this? Guidance documents, such as that from NICE,[5] recommend provision of case management but with little process detail. Its effectiveness is not yet empirically researched in autism and for that reason, the model is vulnerable within a highly stretched resource environment. A potential supplement for the physical key worker within case management is the digital navigator: a person who is able to support both clinician and patient in real-time data streams using and implementing digital health

	Immediate implementation	Medium term
Early detection and care	Using autism monitoring with new evidenced tools consistently in health visitor protocols and possibly education assessments. Adjunctive use of digital health technologies for parents and practitioners to aid early stepwise ascertainment. Reorganisation of practitioner training and practice towards implementation of interventions with evidence for effectiveness in improving early autism-related skills and behaviour and supporting families.	Incorporation of updated monitoring into an ongoing integrated shared care record, co-produced by families and services. Aggregation of large data sets and analytics from integrated records to build a learning health system, which would support a probabilistic decision tree algorithmic approach to step-wise ascertainment.
At diagnosis	..	Evidenced family support around diagnosis with psychological support and psycho-education.
After diagnosis: immediate care	Family-focused early intervention with proven effectiveness in improving child social communication, and minimising negative impacts of restricted behaviours or sensory sensitivities, or other relevant developmental outcomes and parental wellbeing or family functioning, in a sustained way throughout development.	Integrated health system developments including digital shared care records, large data sets, and analytics to help symptom tracking, to predict when a child and family health or wellbeing is at risk, and to trigger referral to step-up or step-down additional support and intervention as needed.
Longer-term care	Step-up care solutions for co-occurring conditions in autism such as anxiety, depression, obsessive compulsive disorder, and behavioural challenges. Digital care navigators making key worker case management to good standard a realistic possibility.	..

Table: **Steps to implementation of the integrated care pathway**

technologies in clinical care. Such digital navigators could be a solution to ensuring that digital health technologies are implemented as designed and intended into clinical pathways.[78] Large health-care systems (eg, Kaiser Permanente, an integrated managed care consortium in the USA[79]) offer early examples of efforts to configure clinical workflows and app implementation to support integration into the busy clinical setting. For example, the digital psychiatry clinic in Boston, MA, USA[80] ensures that apps are a core part of treatment by embedding them in clinical workflows, emphasising shared decision making, measurement base care and therapuetic alliance.

The aim of the digital navigator within our proposed care pathway is to improve the ability of clinicians to use digital tools by building confidence through training and support. To minimise digital exclusion, digital navigators would be available to train and upskill patients in how apps and other digital tools can be used to support self-management and facilitate shared decision making about treatment. We envisage the digital navigator to be a key member of the autism specialist team who would make recommendations for stepping up or stepping down care. They would have the skills to interpret real-time data streams collected through digital remote monitoring platforms and to work with keyworkers, patients, and their families or carers in developing treatment plans informed by remote monitoring assessments. NICE[5] advocated regional specialist autism teams (which could be virtual teams, including multi-disciplinary and cross agency components), who would lead and coordinate autism specialist care in a locality. Such teams would be the obvious location for a digital health navigator process, with members of the specialist team communicating digitally with families to flag emerging concerns and provide responsive step-up care or advice if required. The summary in panel 1 illustrates

how digital health technologies could support and enable a new digital care pathway for autism. Rodriguez-Villa and colleagues[80] provide a detailed description about how the digital navigator role might be applied in practice within psychiatry health-care pathways.

Conclusion and future directions
In this Viewpoint, we have highlighted how models of management for long-term conditions, along with current evidence on interventions for autistic children, can be combined to support an integrated, proactive, and phased developmental model of management of autistic children's support needs—from pre-diagnosis, through early development, to later childhood.

Before formal diagnosis, there is evidence from randomised controlled trials to support the value of parent-mediated interventions from infancy, to optimise family resilience and child social development. Post-diagnostic psycho-education and adaptation support should be followed by an evidenced, time-limited, parent-mediated social communication intervention to optimise the goodness-of-fit of the child's social environment and increase family empowerment and resilience. Interventions that have demonstrated longer-term effects on autistic children's development should be prioritised. Family key working should ideally be introduced during this time within a local autism virtual expert team, to extend support and reinforce family resilience. Later, there should be timely access to step-up care if needed for emerging secondary problems. Case management continues to support the family as needed through predictable transitions and unpredict-able life events. The table outlines a stepwise model for the implementation of the care pathway that we are proposing.

We have focused purposefully in this Viewpoint on early years development (up to age 11 years), but this is

not to disregard the important need for focusing similar conceptual thinking and studies on the experience of autistic adolescents and adults. Conceptually similar pathway models could be adapted for them, with the application of supported self-care through focused intervention models, including an approach based around key workers and the availability of stepped specialist care when necessary. The focus on appropriate environmental adaptation to neurodiversity relates to the early interpersonal environment of the family for younger children, but later in the lifespan needs to be expanded into adjustments in the social and workplace world, as well as in the community. This is a conceptually coherent extension of the initial family-focused work that we advocate, but it clearly extends beyond health care into social advocacy and planning.

The elements of this integrated detection and care pathway have also been adapted conceptually into a theory of change model for low-resource settings globally, with identification of distinct challenges identifiable in different contexts.[8] For instance, the PACT intervention has been adapted for delivery by non-specialist health workers in south Asia, with successful implementation trials[81,82] suggesting efficacy, and the use of evidence-based intervention practice in low-income and middle-income countries. Clinicians, commissioners, and health providers internationally now have an opportunity to promote efficiency by evolving practice towards proactive evidenced care in the context of self-management and a stepped-care framework.

Further research will be needed to test whether combining these components in sequence, as described in this Viewpoint, would indeed confer additive value on long-term outcomes or child and family wellbeing, and whether it would be cost effective in doing so. More detailed partnership work and co-construction needs to be achieved, particularly with regards to the involvement of autistic adults and young people in the design of their own care, including garnering the views of those less able to access traditional methods of communication and co-working.[83] In addition, innovations around digital health management will require careful partnership work to ensure new developments are feasible, acceptable, and accessible to all families, including the most vulnerable. An active learning organisation pathway will facilitate ongoing meaningful collaborative working with stakeholders at every stage of the design and evaluation process.

Contributors
JG initiated the paper and led on pre-diagnostic and post-diagnostic pathway elements. SB and JA led on drafting digital health technology elements. KL led on the peri-diagnostic elements. JG led and all authors contributed to the final drafting.

Declaration of interests
JG is a director of IMPACT CiC, a not-for-profit community interest company set up to provide professional training in the paediatric autism communication therapy intervention for the NHS and internationally. JA and SB are Directors and shareholders of CareLoop Health Ltd, which

develops and markets digital therapeutics for schizophrenia and a digital screening app for postnatal depression. JA and SB are also directors of Affigo CIC, a community interest company that develops and markets digital remote monitoring for schizophrenia and a digital screening app for postnatal depression (Affigo CIC was the predecessor to CareLoop Health Ltd and will cease to exist from May 1, 2022). The Affigo and Careloop companies disclosed have no relevance to autism or the topic under discussion here. JG is a UK National Institute for Health Research (NIHR) Senior Investigator and SB is an NIHR Research Professor. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

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