NHSE WORKING PAPER –
A NEW EARLY CARE PATHWAY FOR AUTISM – CHILDREN AND FAMILIES

"Proven and sustained support from day one"

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1. INTRODUCTION

Statement of the problem

Autism is a priority, including within the NHS Long Term plan, because of its prevalence, the poor outcomes experienced by autistic people and their enduring impact for individuals, families and society. Prevalence estimates are consistently 1-1.8% globally (Elsabbagh et al 2012). Just one reflection of the overall impact of the condition is the estimated £1.5 million lifetime individual health and societal cost in the UK ($2.4 million in USA) for ASD with intellectual disability (£0.92 million/$1.4 million without intellectual disability); a total £32 billion in societal costs per annum in the UK (Buescher et al 2014; exceeding those of stroke, heart disease and cancer combined for instance). Two characteristics of ASD are likely to be relevant to such high economic and societal impact; firstly, the lifespan-enduring nature of support needs for many people and secondly, the core difficulties in social functioning and cognitive flexibility that tend overall to reduce social independence, thus impacting on the family, education provision and social structures in a way that is highly costly.

Making an effective and efficient response to the extent of this public health priority poses new challenges for health and care systems. The current pattern of provision in the UK (as well as internationally) is patchy, reactive, usually received too late and short-term focused, and commonly un-evidenced (Green and Garg 2018).

The proposed solution

This working paper argues for the need to reconceptualize early care provision for autistic children in the light of the early emerging and enduring nature of their support needs and recent developmental research. It argues that care provision needs to ***go beyond short-term reactive care to develop an early proactive, developmentally phased, and scalable programme of support for the autistic child and their family from the earliest opportunity, with timely access to step-up care when needed.***

There is strong evidence that supporting an autistic child through their early development in this way can benefit their social communication skills, as well as reduce restricted repetitive behaviours and sensory sensitivities. It also acts to increase family resilience, something that is key for long-term sustainable care of the child and may prevent emergence of later problems that could otherwise require more intensive responses from public services. This then will represent potential gains in efficiency and cost savings.

This reconceptualisation (Green 2019) builds on concepts and experience gained in the management of other enduring health conditions, alongside new and emerging intervention evidence in autism itself.

- **Developmentally phased interventions.** Previously, interventions did not account for the differences in which autistic and non-autistic children may develop. As a result, opportunities are being missed to help autistic children develop early skills that may be important to their wellbeing and outcomes. We set out how recent developmental intervention research in autism now gives evidential support for the structure and content of such a programme. The paper will set out the template for integrated sequence of developmentally orientated evidenced approaches to optimise social functioning and relatedness with others and to manage co-occurring difficulties.
- **Health system change.** Delivering new patterns of care provision will need parallel innovations within the health system. We will address the potential for digital health technologies to facilitate and realise this programme of care, including digital navigation key working.
- **Readiness.** We will outline innovations ready for implementation now and those needing development for the short to medium term.
- **Efficiency.** We will make the point that these innovations will increase efficiency and therefore should reduce overall cost in relation to the societal costs rehearsed above.

Models from other long term conditions

Evidenced models for managing long term conditions in other areas of health care (for instance, diabetes, depression, hypertension in adults) have a number of common features with relevance to provision for childhood autism. They emphasise: i) the key need for supporting **patient self-care and resilience**; ii) the value of sustained **clinical case**

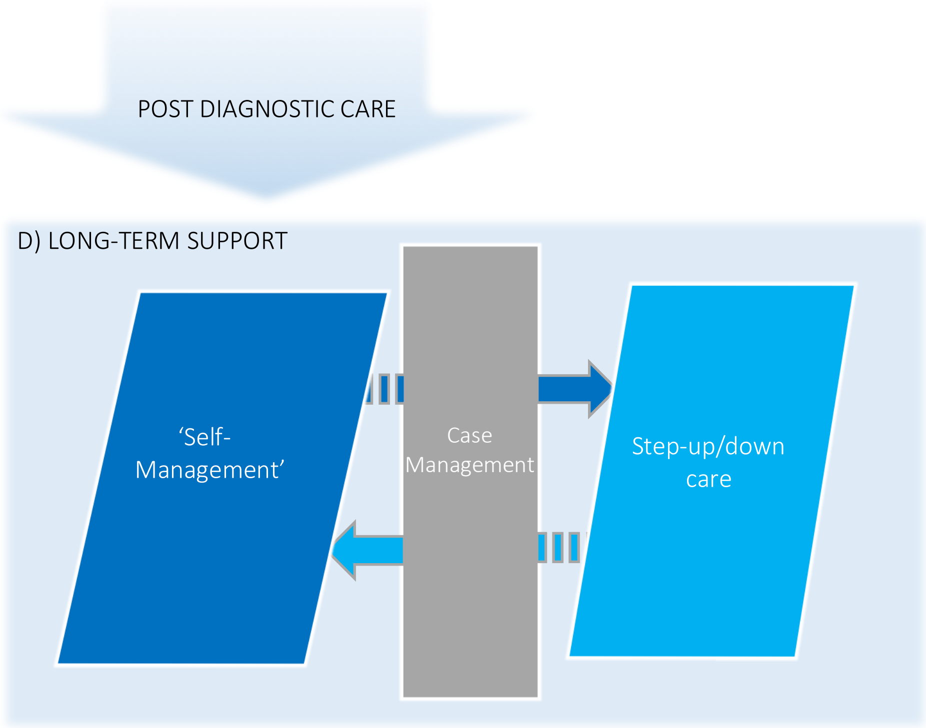
management; and iii) the need for access to **step-up and step-down specialist care** as needed. For autistic children and young people, these models need to be understood in the context of the child's development and the family/carer support network around them. Luckily, we now have evidence-based practice that works in this way, and that is the core of our pathway model.

Self-Management. Evidence synthesis of >1500 studies (Taylor et al 2014) finds 'self-management' to be essential to quality care in long term conditions. But, crucially, self-management is not leaving the patient to their own devices; it is a complex intervention in its own right, requiring focused education, psychological, and systems support to be effective. In this context, it so happens that the currently best evidenced early pre-school interventions in ASD are family-focused and carer-mediated (see below); these can thus be understood to enable ***family self-management and resilience*** consistent with this strategy. Further support for self-care can come from psycho-education and support groups around diagnosis (B below) and creative use of telemedicine and remote clinical monitoring using digital technologies.

Case management. Sustained key working combined with good communication with specialist clinicians is a key part of the 'Collaborative Care Model' for mood and other severe mental illness in adults (Archer et al 2012). The same is also part of NICE recommendations for management of families, children and young people in autism (NICE 2013). Predictable transition stress points (school entry, primary-secondary; transition to adulthood, inappropriate school placement) can be anticipated and managed through proactive case management, which can also facilitate integrated planning with other agencies, including education. However, case management ('key working') can be challenging to deliver in practice, and has to date no evidence in ASD. We will outline below how digital health technology could provide some key solutions for testing in this area.

Stepped care. The stepped-care model (Bower et al 2005) advocates replacement of unequally distributed intensive specialist care (common in the autism field), with a more equally distributed foundational treatment of lesser intensity (although, crucially, still of demonstrated effectiveness), alongside an efficient system of step-up access to more intensive specialist care when needed, returning to the lower-intensity management as soon as is appropriate. Such a model promises better equity and resource efficiency. However, it is essential that the foundation intervention itself is well evidenced (so that this is not a lesser standard of care), and that the system is monitored and 'self-correcting' (i.e. avoiding patients dwelling for long periods of time in low intensity care that is ineffective or in high intensity care that is wasteful). As we describe below, current autism intervention science gives us a unique platform with which to implement such a stepped-care model, since family-mediated intervention is simultaneously relatively low intensity and the best evidence of the primary autism interventions available, providing the foundational treatment against which stepped-up care can happen. We also describe how innovations in the application of digital technologies to healthcare may facilitate step-up and step-down care happening efficiently and in a timely fashion.

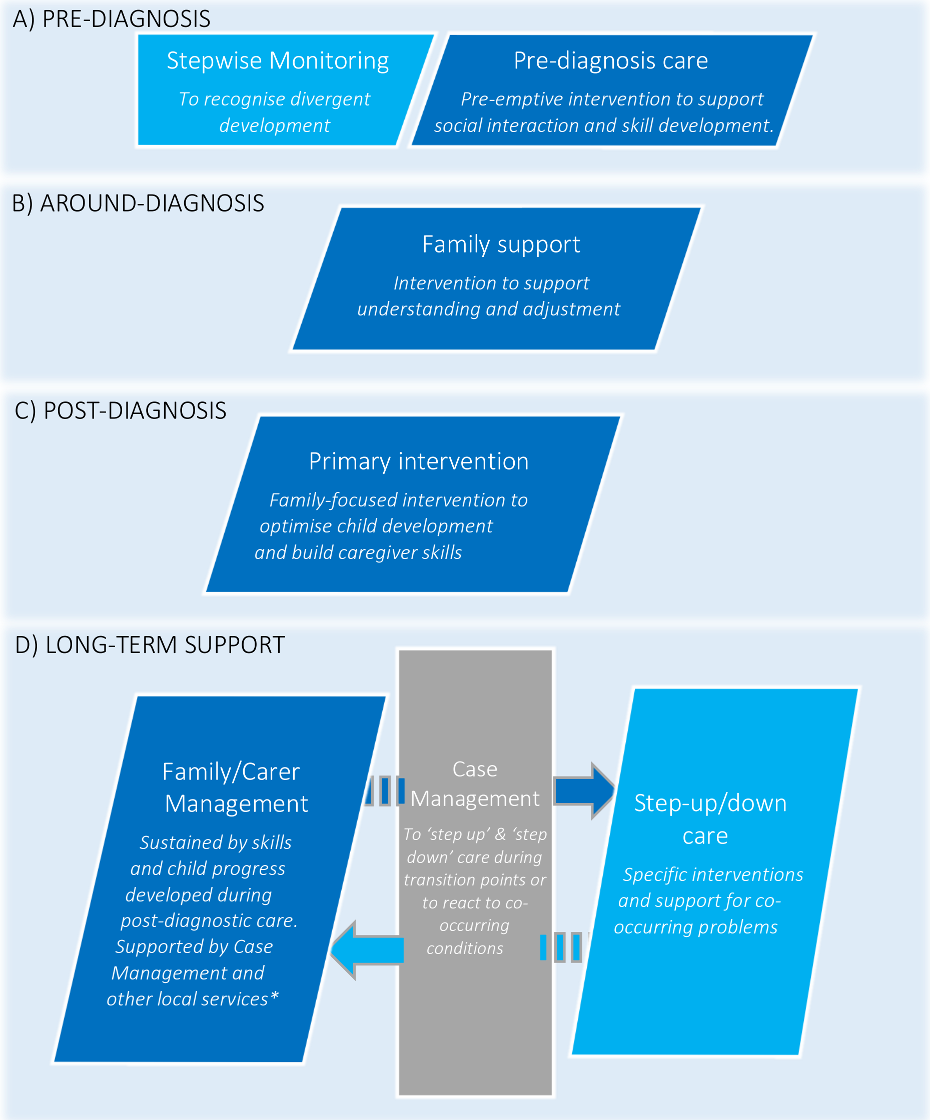
Figure 1 – Management of long-term conditions (see text above)



2. A NEW AUTISM EARLY CARE PATHWAY

Within the context of long-term condition management and current intervention science evidence, we propose a developmental pathway of care from infancy onwards (Figure 1). A sequence of interventions will ideally be combined sequentially over time, giving potential additive effects on a child's development and adaptation.

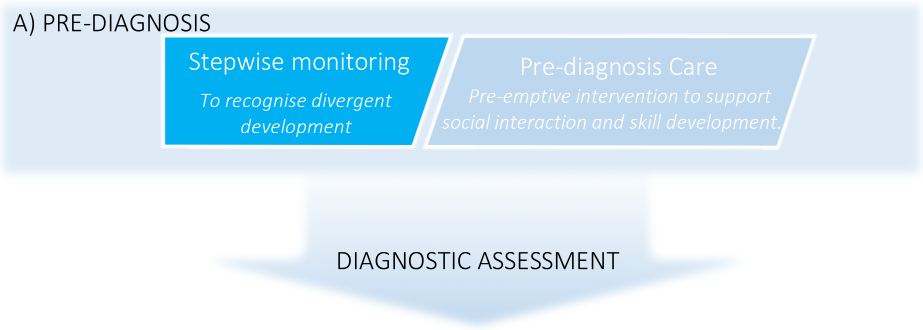
Figure 2 – A developmentally-phased support pathway for young autistic children***



**** Similar pathways could be prepared for autistic adolescents or adults, although they would not take place in the context of a child's early development. This would likely mean significant changes to section A (pre-diagnosis), moving from parent-mediated interventions to directly delivered psychoeducation in Section B (around-diagnosis), and a shift towards interventions that focus on creating a well-adapted physical, rather than interpersonal, environment in Section C (post-diagnosis).*

A) BEFORE DIAGNOSIS

1) Identification and assessment – meeting the ‘detection gap’



Problem to be solved – Inefficient early identification and a ‘diagnosis bottleneck’ in services.

Aim – to develop a stepwise assessment model to avoid the service bottleneck (can be begun immediately).

The developmental period before symptoms consolidate into a diagnosable phenotype can last typically for the first 2 -3 years, but sometimes longer. Two decades of prospective developmental research with infants at high likelihood of developing autism have revolutionized our understanding of this ‘pre-diagnostic’ period and suggested potential routes of intervention.

A developmental approach to the autism care pathway starts here.

The process of early clinical ascertainment leading to diagnosis is currently a major preoccupation and difficulty for services with a ***severe diagnosis bottleneck*** consuming service resource, leading to family anxiety and frustration, and delaying access to early interventions with evidence to help. The common two year wait for diagnosis is unsupportable for a two year old child’s life and their family’s uncertainty about their child’s development. We propose a more sophisticated approach to ***stepwise ascertainment*** linked to ***early evidenced care support***. We have current evidence as to how this could work effectively.

Stepwise ascertainment

Developmental surveillance or monitoring from infancy is now successful in identifying early behavioural signs of autistic traits with increasing specificity and predictive validity as age and development continue. Evidence on the possibility and efficiency of such community identification within a professional network is now established, with measures such as the Social Attention and Communication Surveillance (SACS; Reference) and the Modified Checklist for Autism in Toddlers (M-CHAT; Reference) as well as findings from widely used instruments such as the Strengths and Difficulties Questionnaire (SDQ) evidenced and available for this purpose.

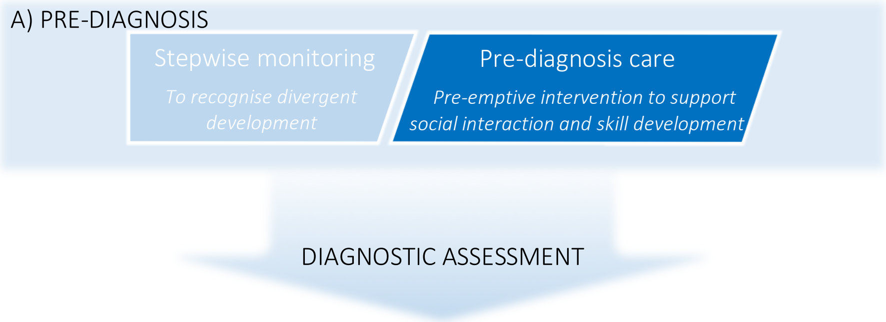
Such methods allow the potential of a stepped approach to assessment, triaging to appropriate support at each stage (as below). Utilising a stepped model of identification plus support within an early care network could mitigate the “diagnosis bottleneck” commonly currently experienced. Many concerns about young children’s development or behaviour may be addressed by working with their interpersonal environment. Identifying those concerns quickly and responding with evidenced interventions may reduce the number of children who would meet diagnostic criteria for autism or benefit from an assessment.

Box 1 - Identification and assessment: Actions, barriers and solutions

The natural workforce infrastructure to accomplish such early surveillance is the health visitor network in the UK with, for instance, the “ages and stages” questionnaire approach to families. This provision is currently patchy nationally, but could be invested in.

- *Short-term*: building autism surveillance more consistently into Health Visitor protocols and possibly education assessments - 2 year goal.
- Application of a second stage needs-based assessment to define appropriate levels of intervention. This could include piloting the acceptability and feasibility of the assessment tool being developed from the ICF Core Sets for Autism (https://www.icf-research-branch.org/icf-core-sets-projects2/other-health-conditions/icf-core-set-for-autism-spectrum).
- *Medium term*: the possible use of digital health technologies (DHT) with families as an adjunct. The vision here is for parent self-identification/monitoring of concerns in the first instance; to get flagged to specialist review for triage. For instance, the ASDetect model https://asdetect.org/ is based on surveillance evidence with planned studies for field testing (https://rdcu.be/cejbS). Implementation of this would need development and piloting, and is discussed in more detail in the DHT section below – 5 year goal.
- *Longer-term*. A Bayesian-type probabilistic decision tree approach to diagnosis will become increasingly possible given DHT capabilities, advanced statistical methods and machine learning; however, there are currently no established algorithms to reliably and accurately undertake this approach – 10 year goal.

2) Evidenced pre-emptive intervention – meeting the ‘care gap’



Problem statement – the lack of evidenced pre-emptive early treatment response to early concerns, which may mitigate later difficulties.
Aim – To implement pro-active early intervention to minimise developmental difficulties (can be implemented immediately).

It is arguably not appropriate (or even ethical) to undertake early identification of this kind unless there is effective intervention support available for identified families. We do now, however, have “pre-emptive” (i.e. pre-diagnostic), parent-mediated social communication interventions, developed from models initially tested in neurotypical child settings, which are thus ethical to implement in a situation where the treated child may not go on to be diagnosed as autistic.

The ‘iBASIS’ infancy intervention is such an approach, based on theory from neurotypical developmental science (eg Tomasello 2003), locating the foundation of infant and young child social communication in the quality and extent of their experience of responsive interaction and communication with key adults. iBASIS (and PACT below) work with caregivers using video-feedback therapy to adapt their responses to match the way the child naturally seeks to interact while playing, leading then to a chain of effect from this caregiver responsiveness to increased child social communication with the parent, which then leads to improved functioning beyond the family. iBASIS is a brief five-month parent-mediated video-aided home-based intervention with parents, which proved feasible to deliver and acceptable to families (Green at al 2012). A randomised controlled trial of the intervention against usual care showed a treatment effect to produce improvement in social communication skills through to three years – the first time such a result has been shown

(Green et al 2017; see Fig 2). A replication study of the same treatment model has been completed in Australia using a sample of 11 month babies presenting in the community with ASD-related developmental concerns, thus mimicking what would happen in community surveillance. The developmental follow-up data of this cohort to three years will soon be published and promises the most substantial test of the efficacy of pre-emptive intervention for autism to date.

Evidenced pre-emptive intervention in infancy for social communication difficulties is becoming routine in some health systems and subject to increasing expectations from families. Pre-emptive interventions can be used as an early response to emerging concerns in ascertainment prior to formal diagnosis, anecdotally reducing the need for later assessments in some cases. iBASIS can be delivered by SALT, psychology, and other senior mental health practitioners after a four day training programme.

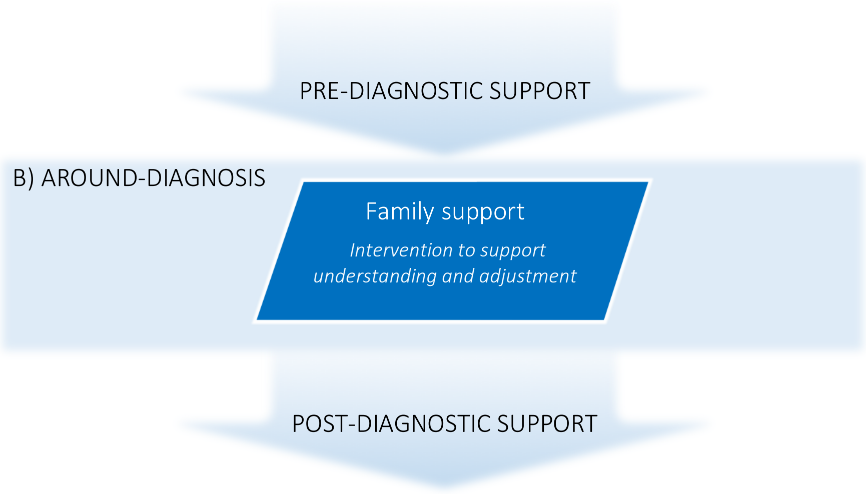
A variety of other pre-emptive intervention responses to developmental problems (without autism specificity) could also be included in this initial response, although they don't have the same level of effectiveness evidence. The **Portage programme** is one well-developed and useful example https://www.portage.org.uk/.

Box 2 - Pre-emptive intervention: Actions, barriers and solutions

Provision of pre-emptive intervention responses of this kind would require a significant re-orientation of clinical services. This would not be appropriate unless there was the evidence of long-term benefit – but such evidence is now established.

- *Short-term* - Evidenced intervention models are now available for immediate implementation.
- A reorganisation of service training towards early pre-emptive response using evidenced interventions.
- *Medium-term* - Health system advances including the development of an integrated shared care record from this time (see below) would help to smooth out the diagnosis bottleneck.

B) AROUND DIAGNOSIS



Problem statement – Lack of evidenced and consistent support for families around diagnosis.

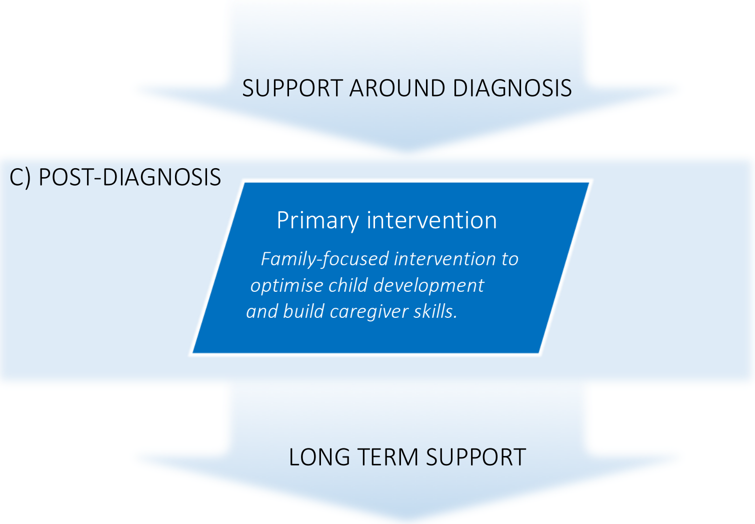
Aim – Introduce universal evidence-psychoeducation that prepares families to provide ongoing support for their autistic child.

The needs of parents around diagnosis are diverse; 20-50% parents show clinically significant levels of mental health need themselves both within this period and on an ongoing basis (Casey et al., 2012; Salomone et al., 2018). Current post-diagnostic provision is a source of significant dissatisfaction to professionals and parents (Crane et al., 2015; Crane et al., 2018; Rodgers et al., 2015). A recent systematic review of UK parental experiences of autism diagnosis emphasised three distinct areas of post-diagnostic need***: informational, relational and emotional*** (Legg & Tickle, 2019). To address informational (and to some extent relational) needs, there are long-standing initiatives to provide group-based parent psycho-education and peer support, some of which have evidence of acceptability or initial observational evidence suggestive of positive outcomes (e.g., Dawson-Squibb et al., 2018; Stuttard et al., 2016). For emotional needs, there is increasing focus within intervention research on adjustment to the news of the diagnosis, long-term stress management, resilience, and stigma protection, with approaches such as mindfulness, cognitive restructuring and Acceptance and Commitment Therapy (ACT; Lodder et al., 2020; Hahs et al., 2019; Jones er al., 2018). Such programmes are not yet formally evidenced for impact, but an ongoing, large-scale, NIHR-funded trial (www.reach-asd.org) is evaluating the clinical and cost effectiveness of a group-based programme blending psycho-education and ACT to address the combined informational, relational and mental health needs of parents in the post-diagnostic period. If shown to be effective, this programme would fill an evidence gap within current NHS provision.

Box 3 - Around diagnosis: Actions, barriers and solutions

- *Short to medium term*. Such "post diagnostic workshops" are common in the current CAMHS service culture and thus the concept and provision is available for re-purposing into evidenced solutions when the evidence is available.

C) AFTER DIAGNOSIS - INTERVENTIONS TO SUPPORT SOCIAL DEVELOPMENT



Problem statement – Current service provision is patchy and focused on poorly evidenced (sometimes invasive) interventions. Evidenced family-focused interventions that build a supportive interpersonal environment around an autistic child are shown to be effective but are insufficiently used.

Aim – Clarification of current best evidenced care that is specific to an autism diagnosis and its application within the care pathway.

Family-focused intervention during the post-diagnosis period currently has the strongest evidence of effectively improving autistic children's outcomes. Significant impacts have been found in children's' immediate social communication or behavior with caregivers, more generalized social functioning beyond their caregiver dyad, and longer-term downstream effects on social communication skill development (Green and Garg 2018). Specifically, ***social communication intervention*** delivered through parents or teachers has the best evidence, and was a 'consider' recommendation in UK 2013 NICE guidance (NICE, 2013) as well as in the more recent UK IAPT autism and Learning Disability Curriculum. Working with and through parents in this way is also relatively low intensity compared to therapist-delivered therapy direct to the child. It has the additional benefit of increasing parental empowerment, family resilience and self-management, providing the early support for family self-management and resilience for providing the ongoing care previously mentioned (Taylor et al 2014).

The authors have been closely involved (JG led the work, KL was a senior researcher) with a UK social communication intervention called ***Paediatric Autism Communication Therapy (PACT)***. This has been tested in several trials, including the three site (Manchester, London, Newcastle) MRC PACT trial, reported in two Lancet publications [2,3], which showed a significant improvement in child autism-related behaviours sustained for six years after the end of therapy (Fig 3; the first time a therapy has shown this for autistic children). This improvement is seen not only for social communication but also for autistic restricted repetitive behaviours, and sensory sensitivities. A further social communication intervention developed in the US (***Joint Attention, Symbolic Play, Engagement and Regulation JASPER*** therapy; Kasari et al 2008), has also shown positive developmental effects at two years after the end of therapy; on improving language outcomes and parent-child social engagement.

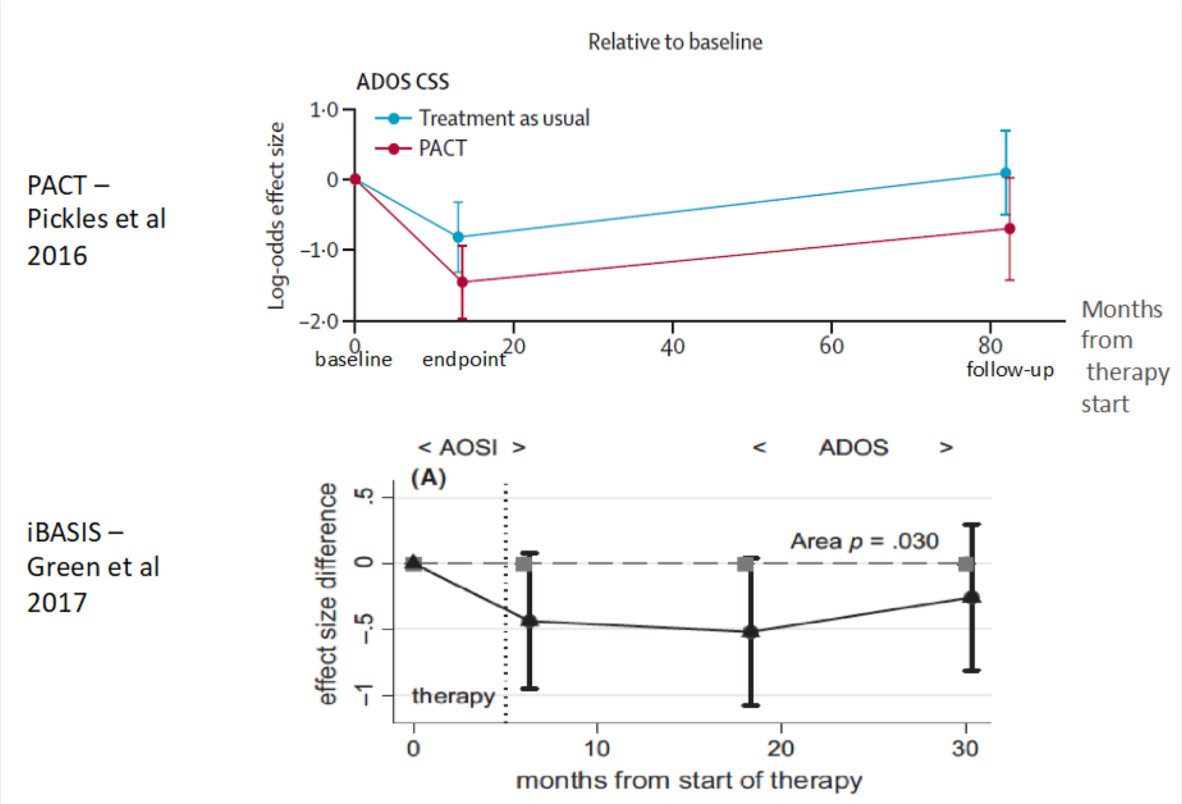


Figure 3 – **Graphic results from trials of two developmental interventions (iBASIS for infants at familial likelihood of autism and PACT for young children after autism diagnosis)** *Both show the effect of the interventions in significantly improving a combination of social communication skills, behavioural rigidity and sensory sensitivities - improvements that continued after the end of therapy. (Reproduced from Green et al 2017, Pickles et al 2016 with permission).*

The PACT therapy works with parents using structured video-feedback techniques to help them recognize and adapt to their autistic child's alternative communication. Working through parents is efficient for therapists whilst being effect, empowers parents with enhanced skills, embeds the work into family life, and improves family self-care and resilience. PACT implementation has been in close collaboration with families and service users. Parent reports on the experience of receiving PACT therapy have been evaluated through independently conducted interviews:

> *"Reflecting on the video was like looking through a magnifier, I could see so much more, now feel I know him better, I'm more skilled in interacting and communicating with him. You have changed our lives."*

> *"I feel like I've seen a big difference and other people have seen a big difference in him as well...he's calmer in himself, he can sit down for longer periods."*

> *"He actually joins in now. When I think back to the very first time that we tried to do this and there was just nothing back…not only that but he's bringing in his life experiences and, you know, to share them with me is lovely."*

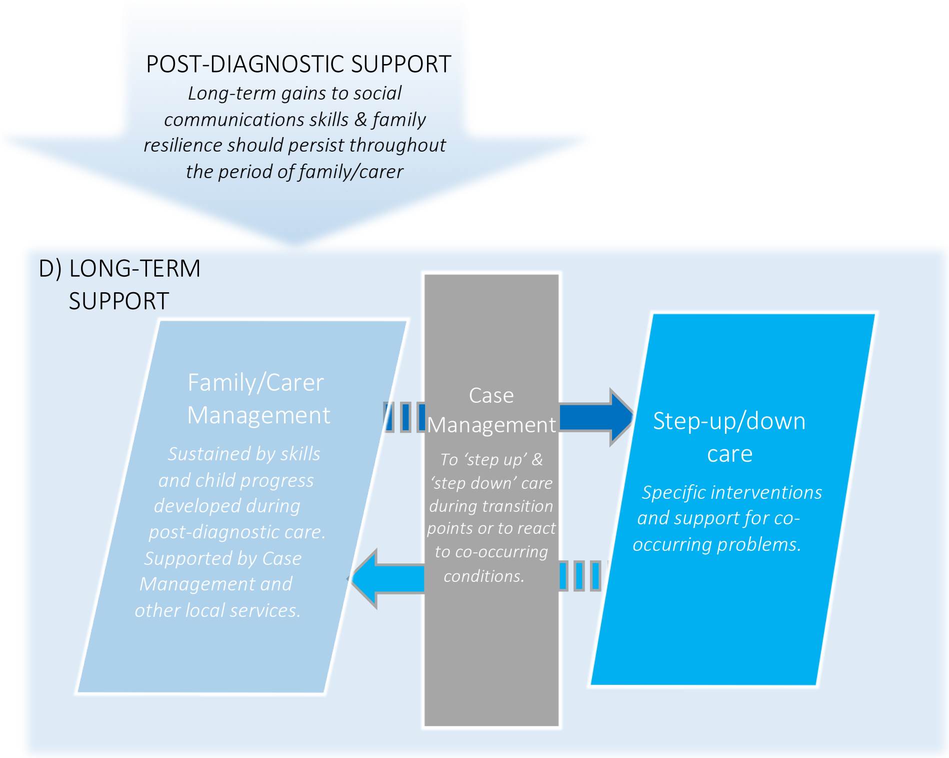
> "*We've been playing quite a lot and M has been communicating quite well… she seems happy and calm - and I feel as if she is trying to tell us things you know."*

The scientific evidence behind PACT has received wide independent recognition. The MRC PACT trial (Pickles et al 2016) was awarded NIHR 'Signal Study' status for its 'high quality design and relevance to UK decision makers'; highlighted in the 2017 UK 'National Autism Project' (Iemmi et al 2017); and a nominated treatment in the DH 'Improving Access to Psychological Treatment' (IAPT) curriculum for Autism and Learning Disability. Recent high quality systematic review of autism intervention evidence from the US (Sandbank et al 2020) has highlighted the leading quality of its evidence. The UK research charity Autistica's independent evidence summary for NHS providers, commissioners and professionals recommends the national implementation of PACT such that, *"when clinically appropriate, all local areas should provide parent-led video feedback therapy as an early intervention for pre-school and school-aged children on the autism spectrum"* https://www.autistica.org.uk/get-involved/world-autism-awareness-week/a-new-communication-intervention. PACT has now been digitised for online delivery of therapy and online training, which further enhances its feasibility in reach.

Box 4 - Primary intervention for core symptoms: Actions, Implementation barriers and solutions

- Professional training in PACT is available nationally. Training in the JASPER intervention is available but less implemented in the UK.
- PACT can be delivered by SALT, psychology, psychiatry, mental health practitioners – and in Asia has been adapted for successful delivery by non-specialist practitioners.
- It can be implemented immediately within current NHS system structures and there are a number of exemplar sites around UK where this has happened successfully.
- A specific PACT implementation project is underway in the Greater Manchester health and social care partnership, supported by GM commissioners and including a structured monitoring of implementation barriers and facilitators.

D) CASE MANAGEMENT AND STEP-UP CARE FOR LATER CO-OCCURING PROBLEMS AND TRANSITIONS



Problem statement: Autism is often associated with other mental health and wellbeing difficulties. We need a system of help for these problems before they have escalated to a crisis point.
Aim: A feasible ongoing system for 'step-up' care for co-occurring problems.

Into the school years, the life for a child with autism (and their family) often becomes stressful and complex, increasing vulnerability to high levels of mental health co-morbidity. To understand these problems, it is important to recognise that the social difficulties for the autistic child in understanding the environment are often matched by those of the environment in understanding the child (what can be called the 'double empathy' problem, Milton 2012). Presenting difficulties are often the result of the autistic child being within a poorly adapted relational, educational or physical environment; equal attention therefore needs to be paid to environment adjustment and management at the individual, familial and societal levels as well as within-child factors. (This is true at the individual level of case management but also relates to a more general level of policy - autism-aware and responsive environments are key for optimizing well-being for everyone).

A specialised approach to individual needs here is therefore often essential in order to accurately understand the difficulties and formulate good interventions. This is where we advocate 'step-up' care provision within autism-specialist teams using evidenced practice. NICE (2013) recommended use of interventions already-evidenced for neurotypical children, with appropriate adaptations for autism. A detailed review of interventions for co-occurring conditions among autistic people is beyond the scope of this review, but summarised in the Box below. Further review may be a useful exercise to support post-diagnostic NHS service planning.

Treatment for Co-Occurring conditions

ADHD	Stimulant medication management; Family guidance
Anxiety	Adapted CBT (Woods et al 2020) Anxiolytic medications

Mood disorder	Adapted psychological therapy or medication management
OCD	Adapted behavioural intervention, CBT, medication management
Concerning (or challenging) behaviours,[1]	Must not just be treated symptomatically; often expression of anxiety, environmental distress, trauma, or physical pain. If remediable cause is excluded, then ASD-adapted individual parent-training has initial good evidence (Bearss et al 2015) and there is early evidence for a UK group-based parent programme 'Riding the Rapids' (Beresford et al 2012). In severe cases, medication management with medications such as Aripriprazole (Marcus et al 2009).

Case Management

Ongoing clinical Case Management ideally would provide support to sustain family self-care and resilience (Taylor et al 2014) and be an interface between family support and multi-agency collaborative care between health, social care and education. Its implementation would reflect a health system designed around autistic people's evolving support needs, rather than one reactive to the 'tyranny of the urgent' (Bodenheimer et al 2002). However, how practical is this? Guidance documents such as NICE 2013 recommend provision of Case Management, but with little process detail; its effectiveness is not yet empirically researched in ASD and for that reason the model is vulnerable within a highly stretched resource environment. Nevertheless, it has clinical face-validity and could be facilitated by, for instance, newer DHTs and online platforms (see discussion on DHT below).

As part of individuation in development, many autistic children and adolescents will increasingly set their own treatment goals in collaboration with families and professionals. These goals may appropriately differ from those established with families in early childhood.

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[1] We suggest the term 'concerning behaviours' in this context. There is widespread (and often understandable) resistance from parents and others to 'disruptive/oppositional behavior' terminology in this context, which can be felt to stigmatize parenting and channel families into CD/ODD 'parent-training' intervention; an important dynamic behind so-called 'Pathological Demand Avoidance' concept.

There is the important process of incorporating autism within the individual’s felt identity and the usefulness of diagnostic descriptors as part of that. In adolescence, intervention work increasingly focuses on the adolescent themselves, at the service of their adjustment into adulthood and transition planning. There is emerging evidence for effective intervention models for these problems in ASD adolescents with good cognitive ability (Wood et al 2021) but less good work on solutions for the developmentally and cognitively delayed.

CARE PATHWAY SUMMARY

Models of management for long term conditions along with current evidence on interventions for autistic people can be combined to support an integrated proactive and phased developmental model of management of autistic people’s support needs, from pre-diagnosis, through early development, to their transition into adulthood.

Before formal diagnosis, there is preliminary evidence to support the value of parent-mediated intervention from infancy to optimize early social development. Post-diagnostic psycho-education and adaptation support should be followed by an evidenced time-limited parent-mediated social communication intervention to optimize early social development, and increase family empowerment and resilience. Interventions which have demonstrated long-term effect 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 more intensive step-up care if needed for emerging secondary problems. Case Management continues to support the family as needed through predictable transitions and unpredictable life events.

Much of this pathway, as we have seen (viz A,C,D above), is now evidenced with specific interventions. Clinicians and commissioners now have the tools to promote efficiency by evolving practice towards such pro-active 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 would indeed confer additive value on long-term outcomes and/or child and family wellbeing; or be cost effective in doing so.

There is more detailed partnership working and co-construction 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 (Leadbitter et al., 2021). In addition, innovations around digital health management will require careful partnership working 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.

3. NEW HEALTH SYSTEM DELIVERY MODELS

Creating a feasible pathway of pre-, post- and long-term support for autistic people will require significant work to re-design the provision of health and care services. This section sets out some of methods, infrastructure and innovations that could help deliver this change.

a) Co-construction of pathways and materials

Of crucial importance to any innovation in care provision is meaningful partnership with stakeholders, including autistic people and their families and carers. In the UK, there is now a much greater emphasis on community priority-setting (Roche et al., 2020). Documented priorities for the autism community include interventions to improve communication, language and mental health and support for parents/carers to better understand and care for their autistic child (James Lind Alliance, 2016). This proposed new care pathway reflects these priorities. There is also movement within both research and service re-design towards participatory methods with stakeholder viewpoints and experiences at the centre (e.g., Lam et al., 2020; Crane et al., 2019). Views of parents/carers have been sought on several aspects of the pathway outlined here; for example, pre-emptive care (Stahmer et al., 2011; Fletcher-Watson et al., 2017), family priorities for early intervention (Leadbitter et al., 2018) and parental perceptions of post-diagnostic social communication intervention (Leadbitter et al., 2020). Stakeholders have been involved in the co-design and evaluation of some key elements. The post-diagnostic intervention programme evaluated within the ongoing NIHR-funded REACH-ASD trial was developed through iterative co-production with parents, autistic individuals and a range of professional stakeholders and detailed qualitative participants feedback supported the acceptability of the new programme pre-trial.

b) Opportunities from Digital Health Technologies (DHT)

DHTs 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. The COVID-19 Pandemic has demonstrated that major changes to the manner in which NHS, education and social care services are delivered is achievable.

Digital health infrastructure

The idea of **co-ownership of health records** between families and health systems is well-established in paediatric healthcare; there is no reason why this could not be incorporated into the autism pathway. Indeed, given the motivation and engagement of most families, it should be an ideal development. The cornerstone of any coproduction approach is a single integrated digital healthcare record. Such a digital system would bring together in one place all that is known about the patient and would be accessible by all those involved in the coproduction of care. This would necessarily be a multi-agency approach, including health care, social care and education with the patient and family as key contributors. Such a system would be able to track the patient over the full life-course as set out in the model in Figure 2 and may be a necessary pre-requisite for delivering a case-managed, stepped-care system as illustrated in Figure 1. We envisage that such a system would facilitate communication, shared decision-making with families, and provide the foundation for co-ordinating a multi-agency approach.

The barriers to such an approach are not technical; the technology to do this is readily available and widely used, such as secure cloud infrastructure. We anticipate the barriers to such an approach would be around information governance, clinical governance, ownership, accountability and acceptability to patients, carers and healthcare providers. Resolving these questions will enable us to progress to a co-produced shared care record.

From this data foundation we can build a learning health system (LHS) for ASD (Friedman et al 2015, Ainsworth and Buchan 2015). By aggregating data across the population and applying data analytics we can develop predictive models and generate actionable insights. Data arising from these actions closes the feedback loop of the LHS, driving new insights with additional data.

Smartphones have great potential within the digital health infrastructure, including: (i) capturing longitudinal, dense, and multimodal physical and mental health data for use in diagnosis and monitoring; (ii) analysing data using advanced statistical approaches or, in more recent times, machine learning, to generate clinically actionable insights and predictions; and (iii) widening access to treatment pathways such as digital health interventions delivered via apps, video conferencing, chatbots or virtual reality. Initially we envisage the smartphone as the primary mode of collecting patient generated data, but such a system would need to be extensible to enable novel data collection from patients and carers e.g. games, conversational modalities.

Box 5 - Examples of successful application of DHT platforms in healthcare

CFHealthHub is a digital self-care and behaviour change platform to support people with Cystic Fibrosis (CF). The digital platform has been extensively co-designed with people with CF and is now embedded in over 60% of adult CF units in the UK. The CFHealthHub programme has been evaluated in a 19-centre Randomised Controlled Trial. The model of care has been developed using the MRC Complex Interventions Framework with the aim of creating a multifaceted system that supports people with CF and their clinical teams to develop the knowledge, skills and self-efficacy (patient and clinician activation) to support preventive self-care. As such, the evaluation has concentrated on building habits of self-care that create automaticity in prevention; this reduces effort and subjective burden whilst increasing adherence to self-care. The platform has been co-designed with people with CF and is supported by a 140 member national network of CF stakeholders, 'CF Digi Care'. The platform has generated global replication interest with international partnerships developed in the US, France and Australia. CFHealthHub showcases how to optimise care and maximise value for money across multiple long-term conditions.

EMPOWER (Gumley et al 2020) is a digital remote monitoring solution that uses a stepped care model to prevent relapse in schizophrenia. The EMPOWER Intervention was designed to enable participants to monitor changes in their wellbeing daily using a mobile phone, blended with peer support. Clinical triage of changes in wellbeing that were suggestive of early signs of relapse was enabled through an algorithm that triggered a check-in prompt that informed 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. Clinical triage of changes in wellbeing that were suggestive of early signs of relapse was enabled through an algorithm that triggered a check in prompt that informed a relapse prevention pathway if warranted.

The EMPOWER app was developed through consultation with service users, their carers, and mental health professionals. Service user participants have access to the EMPOWER app for up to 12 months of the intervention period. EMPOWER was developed as a flexible user-led tool to: (1) daily monitor the *ebb and flow* of changes in their well-being which incorporates, (2) personalized early warning signs of relapse, (3) enables the delivery of self-management messages directly to service users and, (4) provides a mobile phone user interface to enable service users to review their own data and keep a diary of their experiences.

Pre-diagnosis Identification and assessment

Given the lack of a developmental surveillance infrastructure workforce now in many areas, for instance health visitors, and the increasing availability of DHTs, particularly smartphone applications to help parents observe and interpret their child's behaviour, the opportunity arises for systematic use of DHTs to aid ASD identification, assessment and support. Parents are closest to their infants and most often the first to feel concerns about their development. Digital apps are increasingly available which provide information to parents 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 https://asdetect.org/ is one evidence-based example with planned studies for field testing (https://rdcu.be/cejbS). Should significant red flags at this initial self-report stage be identified, then the case would be triaged for professional attention and next stage assessment in a stepped-care assessment model. This process would continue until the final step which involves a clinically confirming ASD diagnosis. Relevant protocols for such an approach would need developing, but are increasingly evidenced as feasible – this is a 5 year goal.

Post-diagnosis symptom tracking and reciprocal care planning

One function of a shared care digital infrastructure would be to provide red / amber flags for decompensation or deterioration in symptoms/behaviours, alerting the need for step-up specialist care. Providing such efficient, real-time are pathways is wholly contingent on such underlying digital health infrastructure. A good example of how this can work elsewhere in medicine is the CFHealthHub system (see box 5) in which data from patients and clinicians is brought together with the goal of increasing adherence to treatment (Hind et al 2019).

Instruments that could be used for autism within an online shared-care platform include:

1) **Online standardised symptom interviews** – e.g. https://dawba.info/ which are co-produced by families reporting symptoms in the child and professional experts evaluating them towards a diagnostic output. DAWBA has been extensively used in clinical practice and research and has good feasibility and acceptability.
2) **Digital symptom-tracker applications**. In the general DHT field, there is a proliferation of non-evidence-based healthcare apps, with only around 2%

supported by any original research evidence (Baxter et al, 2020). In autism too, there are increasing numbers of commercial symptom tracker apps (eg – https://tracknshareapp.com/autism-tracker-app/ ; https://www.autismparentingmagazine.com/best-autism-apps/; https://www.bmc.org/sites/default/files/Patient_Care/Specialty_Care/Pediatrics%20-%20Autism/Recommended-Apps.pdf).

3) **Wearables**. There has been considerable work done on child wearables to track neurophysiology and behaviour in young children, mainly in research on understanding arousal and self-regulation. It is a highly data rich resource and given the complexity of child behaviour it has been difficult to date (despite some claims) to translate this into a predictive set of markers for diagnosis. Wearables are not yet near application, but work is ongoing.

Digital Navigation

Analogous to the 'key worker' idea, the possibility of a 'digital navigator', who is able to support both clinician and patient in real-time data streams and using/implementing DHTs in clinical care, is one solution to ensuring DHTs are implemented as designed and intended into clinical pathways (Wisniewski et al, 2020). Large healthcare systems (e.g. Kaiser Permanente; Mordecai et al, 2020) offer early examples of efforts to configure clinical workflows and app implementation to support integration into the busy clinical setting. The digital psychiatry clinic in Boston, USA (Torous et al, 2020) ensures apps are a core part of treatment. The role of the 'digital navigator' would be to train clinicians and build confidence in using digital tools in the clinical setting. To minimise digital exclusion, 'digital navigators' would be available to train and skill up 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/down care. The 'digital navigator' would have the skills to interpret real-time data streams collected through digital remote monitoring platforms and work with keyworkers/patients and/or their families/carers in developing treatment plans informed by remote monitoring assessments. NICE (2013), advocated regional specialist autism teams (which could be virtual teams, including multidisciplinary 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 up emerging concerns and provide responsive step-up care or advice if required.

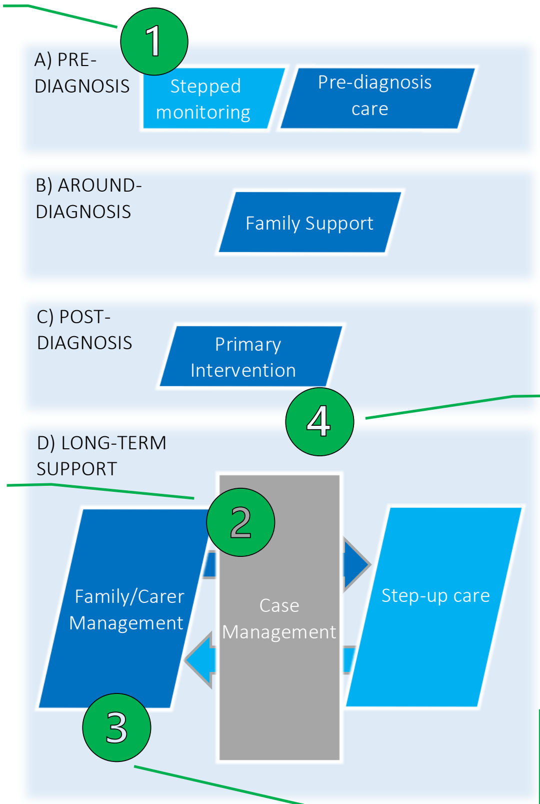
Self-Management content

Internet delivered and computerised therapies, online communities and modular-based internet programmes have a rich legacy and have most commonly targeted depression and anxiety in the mental health sphere. Due to the demand for self-management, they are a means to providing patients and their families/carers with mental health condition-specific support as well as comorbidities and other associated difficulties (e.g. relational conflict). Drawing on cognitive and behavioural strategies most typically, these approaches offer 'on-demand' access to evidence-based treatment strategies. Such technology could be extended to a suite of self-care resources for family use, which could also be applied digitally and this would complement the early family-focused psychosocial intervention within this model. Some core content for such a system has been subject of considerable recent development – for instance the MindEd project - https://mindedforfamilies.org.uk/; https://www.minded.org.uk/.

Workforce issues

A barrier to implementing DHTs across health problems into routine clinical service delivery has actually been the clinical workforce itself. Positioning DHTs in the clinical workflow must be determined. Downloading an app, for instance, is relatively simple. Integrating the data generated by apps into clinical workflows, however, raises a plethora of challenges. While clinicians see the benefits of apps in supporting and delivering care, they are also concerned about issues ranging from safety and privacy of apps, ethics, impact on workloads, and who holds professional responsibility when real-time clinical data appears in the electronic health record. Solving these clinical workflow issues may be a greater priority – and challenge – then any specific technology factors. The rapid development of DHTs presents a challenge in asking clinicians to become experts in data integration into clinical workflows. Education programmes have not caught up with the rapid developments of DHTs and their potential use in service delivery; although, the 'digital navigator' role, highlighted above, may be one solution to integrate data into treatment plans and build a digitally confident and enabled workforce.

This graphic shows in summary how DHT could potentially support and enable different parts of the new care pathway described above.



1: Digital Apps could help parents track their child's development and share info with professionals. This could help services respond to families concerns earlier & potentially reduce the bottleneck in autism diagnostic pathways.

2: Co-owned health records could enable autistic people/families to take ownership of their care. Autistic people/their carers could use an integrated digital record to track changes in their wellbeing while self-managing and 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 & analytics from integrated records could potentially build a Learning Health System, where it becomes possible to predict when a person's health or wellbeing is at risk.

4: Digital Navigators could show autistic people/families how to use shared health records (point 2) & digital self-management content (point 3). They could help coordinate requests for 'step up' support through a digital case management system.

3: Smartphone apps, managed online communities & content could deliver low intensity supports on-demand. A suite of evidence-bases resources could be immediately available for autistic people & families while self/family-managing.

Box 6 - ROADMAP TO IMPLEMENTATION

We have identified a number of ready-to-implement and near-ready-needing-development solutions to an ongoing developmental pathway approach to autism care.

Evidenced and ready for immediate implementation

- Tools for health visitor developmental surveillance and early identification
- Before diagnosis: Pre-emptive family-focused intervention with evidence for effectiveness in improving early autism-related skills and behaviour
- After diagnosis: Family-focused early intervention with proven effectiveness in improving social communication and restricted/sensory behaviours for six years after treatment end, and improving parental wellbeing.
- Step up care solutions for co-occurring conditions in autism such as anxiety, depression, OCD and behavioural challenges.

Medium-term possibilities

- Evidenced family support around diagnosis with psychological support and psychoeducation (evidence in development).
- Use of digital health technologies to aid early stepwise ascertainment
- Integrated health system developments including digital shared care records to help symptom tracking and need for step up care with autism specialist teams
- Digital 'care navigators' making key worker case management to good standard a realistic possibility.

About the Authors

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Declaration of Interests

JG is a Director of the IMPACT CiC (https://www.pacttraining.co.uk/), a not-for-profit Community Interest Company set up to provide professional training in the PACT intervention for the NHS and Internationally. JA and SB are Directors of Affigo CiC (https://www.affigo.io/), a not-for-profit Community Interest Company designed to make digital mental health products commercially available in the NHS.

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