

## We cannot accept another Whorlton Hall. We need better evidence of what works.

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For decades, we've failed to build more appropriate care for autistic people and people with learning disabilities.<sup>16,21,22</sup> We need to stop guessing what works and start supporting carers and families with useful evidence. This plan sets out how we can empower services to measure, learn and improve support. Every year the state spends over £5.2 billion on social care for autistic people and people with learning disabilities with inadequate evidence.<sup>4</sup> Investing just 0.1% of that money in research and development to improve the effectiveness of those services would create a £5.2 million springboard for improving outcomes.

## Current issues

### There is no clear evidence about how to provide social care for autistic people.

An Autistica-funded scoping review struggled to find any reliable studies that tested the effectiveness of social care interventions or service models for autistic people. The few available had weak designs, poor participatory methods and small or self-selecting samples.<sup>1</sup>

### The cost of social care for autistic people and people with learning disabilities is huge but outcomes are unacceptably poor.

Even though most autistic people and people with learning disabilities live with their families, councils and the NHS still spend more on long-term care for this group than they do on social care for all older people. This is not strategic investment: it is the cost of failing to support people effectively and seeing their needs continue to escalate. The demand for care among working-age disabled adults is rising faster than for any other group. Many of the services needed to meet that demand will struggle to survive the financial impacts of the COVID pandemic.<sup>2,3,4,5,6,7,8,9</sup>

### We have failed to protect autistic people and those with learning disabilities during the pandemic.

Care settings for these groups were among the last to receive adequate supplies of PPE and testing during the peak of the coronavirus pandemic, even after the Government belatedly prioritised care homes for the elderly. Poor quality data means we cannot yet tell how many autistic people died from COVID-19 but deaths in care settings where autistic people and people with learning disabilities live almost tripled from the previous year. That jump was more than double the increase in deaths among the general population and was higher than the rise seen in other care homes.<sup>9,10,11,12,13,14</sup>

### The NHS's Transforming Care Programme risks being compromised.

NHS England has made significant progress moving people out of inpatient care, particularly adults with learning disability. However, these successes have been offset by more autistic adults being recognised within inpatient services and autistic young people entering those settings because social care has not met their needs. To achieve Government targets the NHS needs "more appropriate" community care to be available;<sup>15,16,17,18</sup> there is no current evidence on how to develop that support.<sup>1</sup>

### Autistic people have diverse support needs.

Autistic people need different forms and levels of care at different points in their lives. Some adults may need time-limited, low intensity supports, like peer support, befriending schemes or community activities. Other autistic people need more intensive residential care or supported living arrangements for long periods. The evidence around all of these forms of support is unsatisfactory.<sup>1,3,8,19</sup>

### The community desperately wants this addressed.

Autistic people, families, professionals, and researchers identified "What are the most effective ways to provide social care for autistic adults?" as their third highest research priority.<sup>20</sup>

## A plan for progress

### Step 1: Build capacity and infrastructure for better quality social care research

We're stuck in a vicious cycle with autism social care science where: (i) experienced researchers do not see it as a promising field for securing funding or having impact; (ii) less experienced researchers do not have routes for learning vital skills; (iii) funders receive poor quality applications and do not invest in the field; and (iv) professionals and commissioners are left without research evidence that meets their needs. There are many studies describing individual cases or grand theories but there is barely any practical evidence on what works.

### A. The Department of Health and Social Care, Health Education England and public research funders must invest in nurturing a new cohort of social care researchers.

NHS England's forthcoming National Research Strategy for Autism and Learning Disability could support this effort. The sector needs researchers who can design and run high quality participatory studies, gather and analyse data about existing practice and trial new innovations. This may involve encouraging experienced scientists from other fields to adapt their expertise, and setting up PhD or junior research funding streams to support new talent.

"You don't need a bunch of journal publications to tell you autistic people deserve high-quality care. But we desperately do need research to tell us what works best and how that can be delivered successfully. Without this, there'll always be another Whorlton Hall."

"We want to spend our money wisely on services that enable people to have the best possible quality of life, but without evidence of what works, it's impossible to know if we are making the right decision."



## A plan for progress continued...

**B. Public research funders should invest in developing and testing a self-generated individual goal setting measure for autism social care research.**<sup>23</sup> People have different priorities for their support. Identifying a reliable way to measure personal progress would enable other studies to draw more nuanced and informative conclusions about autistic people's quality of life in care.

**C. The Department of Health and Social Care should trial innovative approaches to upskill and fund care staff to collaborate on research.**<sup>24</sup> Social care professionals must be supported to implement evidence and build a culture which values new research. Care professionals' expertise is critical to foresee practical issues studies need to adapt for. Without funding for locum cover, services do not have capacity to help design and run impactful research.

### Step 2: Pump-prime studies in the effectiveness of different social care models & interventions

There is so little good evidence on how to improve social care for autistic people that one-off studies will have little impact. Autistica recently brought autistic people, families, care providers, commissioners and research funders together for a summit to identify the most critical evidence gaps and develop ideas for kickstarting more research:<sup>22</sup>

“Our son’s experience was mixed. He did have appropriate care provided by staff with humanity, common sense and enthusiasm. Unfortunately, in his final supported living placement, positive attitudes were discouraged, families’ advice was dismissed, and most staff did not understand how Danny managed his autism or what he was capable of.”

**D. Pragmatic trials of different social care models to help commissioning decisions.** Running quasi-experiments between local areas who currently fund wildly different care models could rapidly (and more affordably) expand the amount of evidence available on different service approaches and interventions.<sup>23</sup>

**E. Testing the feasibility, acceptability, and validity of measures of distressed behaviour among people who speak few or no words.** Identifying physical and emotional distress earlier and more accurately could help care services pinpoint causes of distress and respond with environmental adjustments. This should help reduce the use of restraint and psychotropic medications. Wearable technology may be one route to explore.

**F. Audit autistic people diagnosed in adulthood about their experiences of seeking and accessing social care services.** Improving people's experiences of accessing care is key to their overall outcomes and quality of life. Exploring past experiences could help identify ways to improve pathways to support in future.<sup>23</sup>

**G. Test whether autistic people who have been through support intervention(s) could become paid peer-supporters for others in similar circumstances.** Low intensity supports may help improve outcomes for many autistic adults and prevent needs from escalating. The acceptability, feasibility and effectiveness of interventions like peer support, enablement, advocacy and befriending needs to be established.<sup>23</sup>

**H. Continuing foundational research into residential care for older autistic adults.** Many autistic people will need residential care as they age, just like non-autistic people. Yet we know virtually nothing about how to improve elderly care for autistic people's needs. A co-designed Autistica study is currently identifying research questions and building a database of recruitment partners for future studies.<sup>19</sup>

### Step 3: Make improvements sustainable with a new funding settlement for social care

Politicians across the political spectrum now recognise the urgent need for a new funding arrangement for social care.<sup>8</sup> Although much of the focus falls on elderly care, it's critical to remember that care for working-age disabled adults, particularly those who are autistic or have learning disabilities, makes up the largest proportion of costs. Stages 1 and 2 of this plan can only be successful if gains can be sustained and if the system becomes more resilient.

Services cannot innovate without certainty and room to breathe. The Government must set out a realistic plan for a new funding settlement for social care that treats improving care for working-age disabled people on a par with improving care for older people.<sup>22</sup> As a country, we cannot continue to let down people who need our care and support to ensure accessibility for those who may need these services most.