DATA 1 and SUCCESS

What is DATA 1? Digitally Acting Together As One (DATA 1) aims to deliver a major scientific breakthrough that will allow the creation of data tools that can improve service delivery across different providers including health, education and social care. These tools will: (i) allow early identification of need and (ii) enable frontline practitioners to organise efficient and effective multi-agency responses to people who would benefit from support.

Why is this scientifically significant? The simplicity of describing a scientific challenge (e.g. 'fly to the moon' or 'develop a vaccine for covid-19') can often mask the inherent difficulties. DATA 1 needs to overcome numerous challenges before genuinely useful data tools can be created, including: the technical problems of connecting and visualising data; the ethical and legal issues that need to be addressed; engagement with the communities served by the tools; and the imperative of producing a tool that can be readily used by practitioners from a range of different organisations. It is therefore unsurprising that a 'gold standard' data tool for public service delivery does not currently exist anywhere within the world - testimony to the difficulties associated within this scientific challenge.

Why is this of societal significance? The covid-19 pandemic has lifted the lid on the costs of a fragmented system. For example, the pandemic highlighted the large numbers of vulnerable children 'under the radar' of organisations with safeguarding responsibilities. The unavailability of connected information made coordinating a multi-agency response extremely difficult despite the <u>same families</u> requiring support from multiple organisations. These problems played out against the backdrop of rising inequalities with service providers finding it increasingly hard to deliver the holistic support needed to address the root cause of many needs. The creation of a 'gold standard' data tool would transform public service delivery, and improve the support offered to hundreds of thousands of people.

How will we tackle these challenges? A wide range of data tools could be created if we can achieve the necessary scientific breakthroughs. These tools would empower policymakers, communities, and practitioners to tackle the numerous problems that currently plague our society. However, the logistical difficulties associated with trying to simultaneously create a number of data tools would prevent timely progress being made. Thus, our strategy is to focus on the creation of one tool within a single geographical locality (the District of Bradford) with a rapid roll out to a neighbouring area (Leeds). Our goal is to produce a data tool that can clear the queue of children on waiting lists for autism assessment, allow earlier identification of undiagnosed autism, and enable children with autism to receive multi-agency support as soon as their needs are recognised. The creation of this tool will require us to find solutions to the challenges, develop the necessary fundamental system architecture, and build the data warehouses. This infrastructure will then allow the production of other data tools at pace, and ultimately result in the generation of a range of tools in the shortest possible time period.

Why Bradford? Bradford is uniquely positioned to act as a pathfinder for DATA 1 as the relevant datasets have already been connected through the Born in Bradford project. Born in Bradford is one of the world's largest longitudinal birth cohort studies and has linked the

data for over 30,000 Bradfordians and demonstrated how these connected datasets can be used to improve outcomes for children and young people. For example, Born in Bradford has shown how routine educational data can be used to identify children at risk of autism, and tested novel approaches to address the problems associated with undiagnosed autism and other developmental disorders (the 'SUCCESS' programme – being rolled out Nationally through support from the Department for Education).

The achievements of Born in Bradford have led to the creation of the 'Connected Bradford' database containing the connected routine records of children across the District. Moreover, the District has developed a plan that prioritises the use of data tools to tackle the inequalities affecting children and young people across the region. The plan has received approval from all of the relevant stakeholders. These factors mean that the infrastructure, mandates, and permissions are in place to test the scientific methodologies.

Why autism? There is overwhelming evidence to show that identifying autism in the early years of life has immense benefits for the child and family. Unfortunately, many children do not have their needs identified until the end of primary school or when they are in secondary school. The issue of undiagnosed autism places health and education services under great strain and creates long term financial costs that could be avoided through early action. For example, many areas (including Bradford) have lengthy waiting lists for autism assessment with children often waiting for many years before they receive the support they need. Furthermore, societal inequalities are reflected within the autism assessment process with children from disadvantaged backgrounds waiting much longer than their more affluent peers. Notably, children from disadvantaged backgrounds with undiagnosed autism are far more likely to also have additional needs that will require a holistic response from a number of different organisations. These factors mean that autism provides a useful test case for the development of a data tool that can tackle such complex problems. In addition, through the SUCCESS programme, Bradford is at the forefront of autism research showing that routine educational data can help ensure children's needs are met as early as possible.

What is SUCCESS? Supporting Understanding of Children's Communication, Emotional and Social Skills (SUCCESS) is a project that uses routine educational data to identify children within schools who would benefit from additional support. These data are then used to direct a teacher led process that can flag children at risk of undiagnosed autism (and other developmental disorders) when the routine data are combined optimally with standardised teacher observations. The project empowers schools to provide support as soon as a child's needs are identified, and subsequently speed access to specialist health teams who can conduct their assessments within school settings in partnership with the school and family.

Please help us to galvanise the District behind this work. Our country is blighted by inequality and many of our most disadvantaged children do not get the support they need. The resulting cost to families is enormous but so are the financial costs that result from failing to support children. We have the opportunity to use the powerful scientific tools at our disposal to tackle this problem in a completely transformative manner. We need everyone across the District to learn more about autism and promote this work across our organisations so that we can improve outcomes for children and young people forever.