The old and the new way of understanding autistic lives: Reflections on the life of Donald Triplett, the first person diagnosed as autistic.

Earlier this month (I write this in June 2023), Donald Gray Triplett III died at the age of 89, in his home in Forest, Mississippi. Mr Triplett was the first person to be diagnosed as autistic, after he was taken by his parents in the late 1930s to the clinic of the eminent child psychiatrist Dr Leo Kanner. Mr Triplett lived much of his life at a time when little was known of autism, when stigma against those with developmental differences abounded, and when thousands of atypical children were consigned to live away from mainstream society in institutions. On this basis, we might expect him to have had a difficult, unhappy life. But by all accounts, this was not the case. Instead, newspaper articles and his obituaries tell the story of a contented, comfortable man who lived on his own terms (e.g., Donovan & Zucker, 2010; Smith, 2023; Traub, 2023). After graduating high school and college, he worked in a bank. He travelled extensively and, after taking up the game in his early twenties, played golf most days. He was part of the social life of his community, for example, as a regular attendee of its coffee club at the Civic Hall. When a pair of journalists first came to Forest to find out about Mr Triplett's story, several locals reportedly told them "If what you're doing hurts Donald, I know where to find you" (Donovan & Zucker, 2010). In his community, Mr Triplett's neurodivergence does not seem to have been a barrier to acceptance.

As so-called 'Case 1' in Kanner's (1943) early paper describing childhood autism, Mr Triplett has a prominent place in the history of autism. But his story points us towards the future too. In this Editorial, I argue that Donald Triplett's life speaks to the value and veracity of a fundamental shift in autism research and practice that is currently underway; namely, a move from an individualised, pathology-based understanding of autistic lives to a relational, contextual model (e.g., Chapman, 2021; Pellicano & den Houting, 2022).

For most autistic people, under current social structures and systems of care, their lives are less happy and comfortable than that of Mr Triplett. Autistic people are, compared to non-autistic people, more likely to experience low quality of life, poor mental and physical health, educational under attainment, unemployment and underemployment, victimisation, social isolation and premature mortality (Howlin & Magiati, 2017; Lai et al., 2019; Hirvikoski et al.,

2016). In my view, the key objective of autism research is to understand why this happens, so that this knowledge can then be used to address the situation.

For much of the history of autism research, attempts to understand the difficulties faced by autistic people have mainly followed the approach illustrated in Figure 1. Here, the logic is as follows: autistic people are at high risk of a particular outcome, and this must be the consequence of some specific characteristic they tend to have. Usually, in this way of thinking, the individual characteristics studied are assumed to be 'impairments' or 'deficits', rather than mere differences, hence it being called a 'pathology model'. Another common feature of this approach is that outcomes are often narrowly defined according to social norms of non-autistic people, with little consideration given to what autistic people want from their lives.

The pathology paradigm shown in Figure 1 has been dominant in research investigating adult outcomes of autistic people. In this sub-discipline of autism research, much attention has been paid to how individual characteristics (e.g., IQ, level of language, number and type of autistic traits) predict such outcomes as independent living, employment and social integration (e.g., see Howlin & Magiati, 2017 for review of this literature). Some consistent effects have been found whereby individual characteristics do predict outcomes, for example, minimally verbal autistic people being less likely to live independently as adults or hold a job. But, overall, effects have tended to be small, inconsistent and of uncertain generalisability: this individualised approach has not yielded accurate, useful models to predict adult outcomes of autistic children. In consequence, it has not done much to suggest how outcomes for autistic people could be improved.

This reflects fundamental limitations of the individualised, pathology approach to autism research. Thinking of Donald Triplett, if we want to understand how he was able to build a satisfying life (i.e., his 'adult outcomes'), only considering his individual features (e.g., his level of language, his IQ, his autistic characteristics) would result in an incomplete, threadbare explanation. Any valid and useful account of his life must include his environment, such as the parenting he received, his supportive family, the values of the community he lived in, the material resources available to him as someone from a wealthy

family, the degree of flexibility in his workplace, and so on. I do not wish to downplay the influence that Mr Triplett's individual characteristics had but they are just one part of the story, as they played out in a context. From reading about his life, my sense is that Mr Triplett found a niche. What I mean by this is that, with those around him, he worked out a good fit between, on the one hand, his individual characteristics, needs and motivations and, on the other, the demands and opportunities provided by his environment.

The need to accommodate both individual and contextual factors is reflected in Figure 2, which depicts an 'ecological model'. Here, the fact that everyone exists in an environment is accounted for. Specifically, the idea that the environment shapes the person, and the person shapes the environment is incorporated, because all outcomes, good and bad, arise from a dynamic interaction between the individual and their environment that plays out over time. In this way of thinking it is not simply individual differences that cause outcomes; but rather the nature of person-environment fit. Positive outcomes, like those of Mr Triplett, are likely to arise from a good person-environment fit, where the demands and features of the environment are aligned and compatible with the capacities, motivations, and values of the individual. Poor outcomes emerge when the environment makes demands that are impossible and/or undesirable for the individual to meet, given who they are.

The ecological model shown in Figure 2 represents one key component of the neurodiversity approach to autism, along with an emphasis on seeing neurodivergence as difference rather than disorder and centring autistic perspectives in research and practice. It has an ethos of promoting outcomes that matter to the autism community (e.g., promoting wellbeing) rather than trying to 'fix' autistic people (e.g., Chapman & Botha, 2022; Pellicano & Van Houting, 2022). Whilst the foregrounding of an ecological perspective, as part of the neurodiversity movement, is a new development in autism research, it is an idea that has a venerable past. For example, the notion that individual and environmental characteristics interact over time to produce outcomes is central to the social model of disability (Shakespeare, 2006) and to the field of developmental psychopathology (Cicchetti & Toth, 2009). I certainly do not wish to imply that there is no tradition of such thinking in autism research. For example, in the adult outcomes literature, there has been work looking at environmental influences (e.g., school inclusion, parenting, stressful life events) that has

yielded important findings that have implications for practice (Howlin & Magiati, 2017). Over the years various scholars, often autistic and commonly grounded in ecologically oriented disciplines such as sociology and community psychology, have worked to direct autism research towards more ecological ways of thinking (e.g., Chapman & Botha, 2022; Milton, 2012; Robertson, 2010; Sinclair, 2010).

I highlight three advantages of the ecological model over the individual, pathology model for autism research. First, as I have argued above, it possesses more veracity than individualised models, because it better accommodates the fact that people exist in environments that they influence, and which influence them. Second, it is more ethical, as it does not simply locate problems within the individual, but, rather, allows for analysis of how wider contextual factors, including various forms of unfairness at the social level, impinge on individual lives.

The third advantage of the ecological model, compared to individualised approaches, is that research in this paradigm is more likely to identify modifiable risk factors that could be the targets of interventions to improve the wellbeing of autistic people. As such, ecological model research often points towards the need for modification of environments in which autistic people live, rather than placing all the responsibility on autistic individuals to change. For example, work showing ways in which the transition to secondary school influences mental health of autistic children can underpin the development of strategies to modify the secondary school environment to promote wellbeing (Mandy et al., 2016a; 2016b). Similarly, research on the effects of stigma and intolerance upon autistic people (e.g., Perry et al., 2021; Sasson & Morrison, 2019) show the potential value of interventions aimed at improving autistic wellbeing by changing social attitudes of the people around them. A good example of such an intervention is the Learning about Neurodiversity in Schools (LEANS) project, which seeks to foster tolerance and acceptance in primary school children towards their neurodivergent peers. After all, tolerance and acceptance from those in his family and community appear to have been key ingredients in Donald Triplett's successful autistic life.

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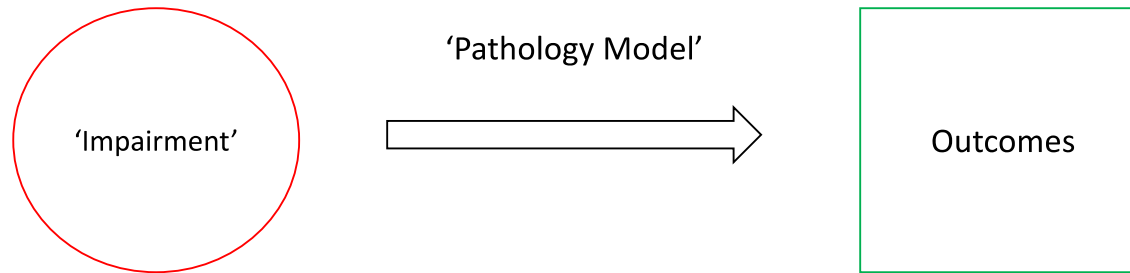
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New and old models in autism research

Figure 1

'Impairment'

'Pathology Model'

Outcomes

Figure 2

Person

Environment

'Ecological model'

Outcomes