'it was...a mixed time really...'

Becoming an adult during the Covid-19 pandemic:

Stories from mothers of young adults with Down Syndrome

Eleri Nia Davies

Trainee Educational Psychologist

Research Conception

RATIONALE

An integrative literature review exploring transition into adulthood (TIA) for young adults with Down Syndrome (DS) espouses the importance of contexts to develop independence, experience increased autonomy, engage in peer relationships and participate in communal/leisure activities separate from family life, finding meaning/purpose in these pursuits, as well as growing through encountering and overcoming challenges.

The instrumental role of parents is highlighted whom invest much physical, emotional and mental effort towards facilitating a fulfilling life for their young adults, often experiencing mixed and dynamically shifting positionings in their role, and worries/fears which may conflict with their hopes/goals. There is a noticeable impact upon their lives and that of the whole family. Professional systems are helpful when practice is person-centred, preparation is early and comprehensive, input is timely, and there is coordination across systems. Moreover, the key importance of collaboration with parents and their young adults is emphasised. However, parents tend to be left wanting and may feel obliged to assume roles contradictory to a collaborative ethos such as 'fighter', 'consumer' and/or 'ultimate transition coordinator' (Detisch, 2007, p. 206).

A scoping review implies that the Covid-19 pandemic (C19P) generally impacted people with DS in a predominantly negative way; although, stories of hope and resilience also emerge (Vaccarino et al., 2022). Young adults with DS were classified as 'clinically extremely vulnerable' which entailed stricter restrictions, and associated anxieties. The factors above intrinsic to TIA were likely significantly impacted. Pueschel (1996, p. 94) describes optimal transition as occurring in the 'least restrictive environment', so what was it like in a nationally-enforced restrictive environment?

RESEARCH QUESTIONS

- How did the C19P impact the TIA for young adults with DS, both during the pandemic and in the longer-term?
- What were these experiences like for young adults with DS and their parents, from the latter's perspective?

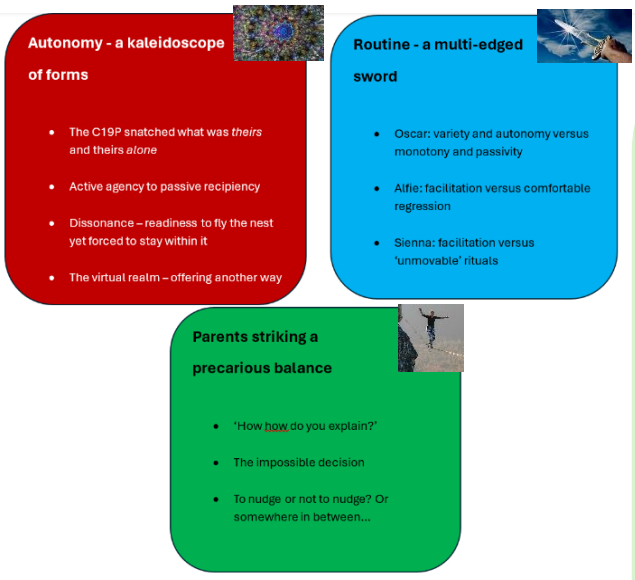
PARADIGM

- Ontology: **Critical realism**
- Epistemology: **Social constructionism**
- Methodology: **Qualitative**

Research Design

PROCEDURE AND PARTICIPANTS	METHOD
Individual interviews, utilising a semi-structured open-ended schedule. Interviews lasted 60-70mins and were conducted on Microsoft TEAMS. The sample comprised 3 mothers of young adults with DS who were considered to have been TIA during the pandemic. Rosie (mother of Oscar), Ruby (mother of Alfie) and Olivia (mother of Sienna).	Interpretative Phenomenological Analysis (IPA) (Smith et al., 2021): this method involves the researcher eliciting participants' experiences as they undergo a process of sense-making regarding a significant event/s or period in their lives. Mothers were asked to make sense of a significant period in the lives of their young adults and themselves (i.e., TIA), as impacted by a phenomenon that affected most people (i.e., the C19P). The mothers held an 'important stake in what (was) covered' (Smith et al., 2021, p. 4). The researcher probed further to explore their and their young adults' experiences, and their sense-making of those experiences. The researcher traversed convergence and divergence across the mothers' phenomenologies, upholding the idiographic commitment in IPA, and establishing coherence within the paradigm. The researcher practiced reflexivity in their interpretation, attempting to 'bracket off' (Smith et al., 2021) their own personal influences.

Research Outcome



Strengths: contribution from experience, long-term focus, accessibility of procedure.

Limitations: omitted protagonist's voice, diversity of sample.

Future: young adults themselves, creative procedures, focus groups?

DISCUSSION

The analysis offers researchers/practitioners nuanced understandings of the autonomy and routine constructs, and an in-depth exploration of the balances struck by parents and families, made more complex and precarious by the impact of the C19P.

The endeavour of developing autonomy should be individually tailored and could be considered in the context of the PERMA model (Positive affect, Engagement, Relationships, Meaning, Accomplishment) (Seligman, 2011). C19P conditions simultaneously constrained and created avenues to pursue autonomy, relating to possession of their own spaces/activities, roles, mindsets, and creative exploration in the virtual realm.

Routines are usually depicted as healthy and were elevated as a resiliency buffer during the C19P. Protective aspects did become apparent, but the analysis also captured perhaps darker sides of the sword, manifesting uniquely for each young adult, whether this be a monotonous tunnel, a comfort zone, or a strict ritual. Practitioners should encourage flexibility, and routines that inspire growth, encompass agency, and complement PERMA.

Parents seemed predominantly alone in striking balances across several axes for their young adults in terms of explaining the C19P, making burdensome safeguarding decisions, and helping their young adults to adapt to post-C19P life. Regardless of contemporary challenges, practitioners should be widening the tightrope and thus aiding the striking of balances.

EPs: direct work – *personal construct psychology tool use and development to explore autonomy*; systemic work – *meta coordination, building professional collaboration, training – theoretical oversight and useful combination – to flourish and to cope.*