**Perspectives of autistic young people on a sense of purpose and on their futures**

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My PhD examines the perspectives of autistic young people (AYP) aged 16 to 25, in relation to a sense of purpose. This has constituted, for these young people, consideration of their futures. I am at the stage of writing up my findings.

Outline

I will begin by sharing some background information to my study. I will share relevant literature that has informed it, my research questions, and some information about my methodology. But I will focus on sharing some of the insights gained so far: themes that I have identified in the data; and I will share words from two of the participants indicating their perspectives. Implications envisaged are then indicated.

Rationale

I have taught AYP at various levels in special and autistic schools since 2006. This included teaching philosophy, and also about careers. I noticed that these students appreciated a focus on Big Questions and philosophically oriented discussions. When beginning this study, I felt I knew about AYP. I had led their annual review meetings; chaired transition meetings, seen them move on from school/ college into the adult world. I felt I knew much about their drives; preoccupations; what often annoys them; what other people say about them. With hindsight, Ihad not been prepared for being surprised during the study: by the ways they were able to share their insights during my conversations with them; how they were able to contemplate their challenges and dilemmas; the clarity and maturity of their thought. I was surprised by what I learnt from them - especially their views on life and how to live it, including sharing their hopes to help and support others, particularly those facing similar situations.

Autistic people are more likely than not, to suffer from mental health difficulties (Lai, 2020, p. 3), suggesting that as many as 70% having co-occurring mental health/psychiatric conditions. ‘Autistica’ (a UK autism research charity), in 2016, initiated research (with the James Lind Alliance) showing that the number one priority of autistic people, their carers and clinicians, regarding research questions that needed to be asked was: ‘Which interventions improve mental health or reduce mental health problems in people with autism?’ When approaching this research, I always had this consideration in mind. Research indicates that higher purpose in life is associated with an array of physical and mental health benefits (Kim *et al.* 2022). In my professional work I have found that to reduce anxiety, AYP particularly need to understand why they are undertaking something and for how long (i.e., they often require goals and time periods to be clarified). Structured timetables over a day/week are commonplace in autistic settings. Thus, whilst this inquiry has hoped to engage the participants in stimulating discussions, it was oriented to explore the potential usefulness of supporting goal-oriented thinking and behaviour over larger time frames. I wanted to find out if exploration of purpose with AYP might offer them a means towards greater well-being and what were their opinions about this.

Literature and Definitions

Leading theorists Damon, Menon and Bronk (2003) argue that ‘meaning and purpose’ are often used interchangeably but that ‘purpose’ is distinct from ‘meaning’ - meaning is a more self-focused conception. I too chose to give purpose sole focus. Investigation of literature involved three main areas: purpose, autism and participatory research. Publications were found in relation to ‘purpose in life’, ‘a sense of purpose’, or simply ‘purpose’. Some authors undertaking studies of youth purpose have conducted research on civic education with young people (e.g., Baulm *et al.* 2023; Quinn, 2019). Research on AYP’s perspectives on purpose I found, was a rarity (Quinn *et al.* 2019). There were no studies discovered talking specifically to AYP on the subject in the UK. Literature on youth purpose was often found in the US in psychology or education. Damon, Menon and Bronk (2003) make the possessor of purpose externally positioned and focused, i.e., they must have a desire to contribute, support or help others, not only themselves. (I informed the participants of the distinction that exists, regarding internal and external conceptions of purpose). These authors describe purpose as ‘a stable and generalized intention to accomplish something that is at once meaningful to the self and of consequence to the world beyond-the-self’ (Ibid., p. 121). I kept an open mind of definitions for my participants. Classification of whether a person ‘had a sense of purpose’, often the objective of psychological literature, was not mine. My aim was to gain AYP’s perspectives on purpose; to see if they might consider it beneficial to include in their school curriculum. I felt that my close-up research with a small sample of AYP fitted with this aim.

How to describe autistic people is problematic and disagreements arise as much inside, as well as outside of the autistic community about this. Kenny *et al.* (2016) explain the ‘identity-first’ or ‘disability first’ debate. Some individuals prefer to be described as ‘a person with autism’; others prefer to be referred to as ‘an autistic person’. Important to my study was to find out if and how diagnostic labels might be affecting the young peoples’ perspectives in relation to their sense of purpose.

Research also illuminated the lack of participatory studies with autistic people. The increasing demand for participatory research from the autistic community urged me to make the study as participatory as possible. Admittedly, I feel that I only achieved this to a certain extent. I also chose to make it phenomenological, in endeavouring to properly convey AYP’s experiences and thoughts.

Research questions

These were my research questions.

1. How do autistic young people (AYP) describe their experiences and perspectives regarding a sense of purpose?
2. What suggestions do AYP offer as to the usefulness of fostering a sense of purpose with them and how might this be done?

Methodology

My chosen methodology was Hermeneutic Phenomenology, drawing particularly on the works of Gadamer. Gadamer propounded iterative engagement with texts (either written/spoken). For me this involved not only the meetings with participants, but I kept a personal journal and had further discussions with them in person and via email. It was a repetitive process of interaction and interpretation; an approach suitable for acquiring deep insight into peoples’ lived experience. The young people’s opinions were gained by merging the statements of more than one participant, as well as including solitary insights. Due to the choice of this methodology and the study’s participatory aspirations, I believe, I have come closer to their perspectives than I might have done with a different design.

Data Collection

Two institutions from Southern England took part. The first was an autistic school for students aged 16 to 19 years. The second was an autistic college for students from 16 to 25 years. Five participants agreed to participate from the school (which acted similarly to a pilot school). Five participants took part from the college. As it was to be as participatory as was feasible, I provisionally suggested for Part 1, semi-structured interviews; for Part 2, focus groups. These were loosely described formats as were methods of responding. Changes to the loose plan were welcomed throughout. And there were some adaptations, e.g., some participants preferred to be in a one-to-one follow-up meeting, rather than in a focus group; one completed responses to questions via email. In making an approach to this vulnerable group and in accordance with ethical working, I avoided focus on the struggles or adversity the participants might have encountered.

Findings

In relation to findings, I found that the participants defied stereotypical views presented about autistic people. In attending to research question 1, their perspectives, the participants’ individuality came to the fore, as well as their capacity to appreciate each other’s viewpoints and to empathise. I identified an overarching theme in the analysis of the data of ‘adversity and overcoming’. From this I discerned four main themes. These were: 1) ‘We are who we make ourselves to be’, 2) ‘Not wanting to be held back by anybody’s anything’, 3) Contemplating purpose in a world of others and 4) ‘Teach people how to overcome barriers to purpose’. All but one of the participants reported that they have experienced micro purpose. One participant preferred instead to speak in terms of having been involved in ‘purposeful’ work.

Research question 2 findings centred upon future advancement of work on purpose and barriers to purpose. This part of the study illuminated the view that partly due to their struggles, AYP put up barriers to purpose. Even those most suspicious of the construct of purpose stated that AYP require more support to be purposeful. They condemned wider societal views towards autistic people, for hindering their efforts towards self-determination and the fulfilment of projects they wish to undertake. They expressed interest and approval in projects for example, which were community-based and in which those participating received feedback from the beneficiaries of the work undertaken (e.g., that of Araujo *et al.,* 2016). Importantly, for their mental health, I suggest, this may provide an opportunity for autistic people to perceive how their lives *matter* in the world (as Moran (2018, p. 147) claims for non-autistic people). The participants in my study appreciated being involved in research that properly sought their perspectives on important issues of life. (It was clear that anyone seeking to help participants to answer future-oriented questions about their own goals and ambitions would have been self-defeating. Only the participants themselves could reflect inwardly and know what most motivates them).

I now provide selected excerpts from two of the participants, one from each institution. I will focus on what they had to say about the ‘beyond-the-self’ aspect of purpose, in which the area of civic duty falls. Pseudonyms are used. Those who appeared to demonstrate a sense of purpose did not do so on a grand stage - it was not ‘world changing’ - nor was it necessarily highly aspirational. Yet they could often see purpose at a micro-level, in the small actions of their lives, such as helping people in their immediate environs. Most were able to consider their futures beyond only jobs or careers and considered themselves as developing and contributing human beings.

Participant 1: Kovu

The first participant I will discuss is Kovu. Kovu was well presented. They appeared highly capable. In fact, they did have high career goals. They were at the time of meeting, aiming to gain A\*s at A ‘level (this is the top grade at public examination in England, usually taken at age 18-19), and were transitioning to university to study science. They also revealed that they had experienced depression. In their conversation, they explained they were coping with doubts about their capacity to live independently (an experience that had been lifelong). They said: ‘*We weren’t sure how much support I’d need’* in the future. Yet, they were very independently minded. They saw university as an escape route – an opportunity to prove to themselves, as well as to those who have doubted them, that they were able to be independent and successful. They felt that they had less agency than their sibling and this was for them, a chance for intellectual freedom too. They stated, *‘I just want to be able to get on with my life the way I want. And not have to be held back by anybody’s anything’.*

Although Kovu was adamant about not having found a sense of purpose, they still demonstrated purposeful behaviour. One example of this was, before taking part in the study, and prior to leaving school, they sent a 12-page document to their school’s senior leadership team regarding how to improve the school. This included wishing work to be done to encourage students to see a future for themselves; wanting to change student views on autism and on being autistic. (Incidentally other participants from my study voice this also). Kovu created this document for others, not for themself – as they would have left and this would not benefit them.

When asked more about their purposeful actions, Kovu advocated ‘pragmatic purpose’. They spoke of how to manage with *not feeling a sense of purpose* – ‘faking it to make it…’ This at least enabled them to get things done (e.g., it enabled them to get on with their A’level studies). They described ‘flipping the perspective’ - flipping the idea of life giving them meaning/purpose as it does not currently – ‘the universe does not give me meaning, I give the universe meaning’. This was the best solution they had come upon. In Kovu’s view, beyond-the-self purpose (i.e., doing things for others) does not require an internal sense of purpose. They discussed the examples of helping their mum when sick, and animal care work. They saw shouldering responsibilities as important and helpful to themself.

Participant 2: Sidney Smith

A sense of responsibility was important for Sidney Smith too. He urged other AYP to ‘be the person that people can lean on, rather than relying on other people’. Sidney seemed highly eloquent and philosophical in his outlook. He had clearly suffered a very difficult time and was accessing therapy. He had endured the loss of a parent, experienced rejection, and abuse from a relative, yet he appeared galvanised (as he said), to ‘become so much more than I ever thought I’d be’. In fact, of all ten participants, Sidney seemed to be the one who most positively claimed to have gained a sense of purpose in relation to his life. When meeting with him, he discussed wanting to become a teacher, and was enjoying a work placement (in a school as a teaching assistant). He described how this was helping him to understand himself and his past. A particular goal of Sidney’s was to one day inspire children with similar needs to his own, to do well for themselves, and to develop a ‘can-do’ attitude. Sidney also explained that negative times enabled ‘the good times to mean something’. He identified that one of my presuppositions might not be correct: Purpose is often found through suffering and adversity, (6/10 participants exemplified this). It might not necessarily be found when contemplating the best moments of their lives. Advice from Sidney was to build on small actions and achievements to become purposeful (e.g., his approach was beginning with making his bed each day. If he had a bad day, then at least he would have a nicely made bed to come home to). He advised, for finding a purpose, ‘open up a dialogue, not just with other people, but with yourself’. And several of the young people spoken to, expressed the same view, that development of self-knowledge was of key importance to them.

Implications

Implications envisaged at this stage, include the following:

* Participants generally saw value in teaching other AYP about purpose. They felt school is a setting in which this probably could and should be addressed. I question whether it should it be included in for instance, documentation such as the UK’s *Character education framework* (Department for Education, 2019).
* The ‘beyond-the-self’ aspect of purpose should be taught (at least for some), practically and explicitly to enable them to see the impact of their actions. This may assist them to see why their lives matter in the world.
* Participants wished for research/society to seek ways of enabling AYP to overcome barriers to purpose; to stop AYP putting up barriers to purpose in the first place. Thus, autistic people should be encouraged to succeed in purposeful projects, i.e., those promoting their self-determination and authenticity.

I would like to acknowledge the participants with my thanks – it was often not easy for them to take part. It took courage to open-up so personally to someone they barely knew.

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