

FATHERS' EXPERIENCES OF PARENTING A YOUNG ADULT WITH DOWNS' SYNDROME

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Background

- Generally, parenting research has focused more on mothers' experiences, rather than fathers' experiences.
- Within the disability literature, there appears to be less research that has focused specifically on Downs' syndrome (DS) as a developmental disability.
- Furthermore, research has tended to focus on parenting experiences at younger ages and at diagnosis, rather than older ages and adulthood.
- Mothers' experiences of parenting a young adult (YA) with DS have been explored (Docherty & Reid, 2009). However, it cannot be said that fathers' experiences are the same.

Aim

To explore the experiences of fathers of YAs aged 18 – 25 with DS.

Who Took Part?

- Nine fathers who were parent to a YA with DS (aged 52 - 68).
- The YAs were: seven male and two female (aged 18 - 24).

What was involved?

- Fathers took part in semi-structured interviews over video or telephone.
- Interviews lasted around an hour and a half and were focused on fathers' experiences of parenting their son or daughter since they have been 18.

Methodology

- A methodology called Interpretative Phenomenological Analysis was used to analyse the interviews.
- This was chosen as the focus was on trying to understand what it is like to parent a YA with DS and how fathers make sense of their experiences.
- All interviews were analysed individually, before carrying out a group analysis.
- This was because whilst all fathers had differences in their experiences, there also appeared to be many shared experiences.
- Therefore the findings reflect the group experience, rather than specific individual experiences. Particular individual differences have been captured in the full write up of this study.

Findings

- Three main overarching similarities ('themes') were identified that nearly all fathers experienced.

Conflicting thoughts and feelings around the current age of the young adult and their experiences.

- Fathers described a range of experiences, including a loss of expectations, and a sense of sadness towards how things were for their son or daughter, in addition to feelings of pride in noticing their son or daughter achieve certain milestones, and gratitude for the relationship they have.
- This period also seemed to bring about feelings of guilt (e.g., concerns about having done enough as a parent, wanting time back for selves, or vocalising some of their difficulties).
- The additional challenges that accompany this stage of development also seemed to make it difficult for fathers to fully accept things as they are.

Conflicting thoughts and feelings about the next steps of the young adult's journey.

- Fathers vocalised wanting to promote independence for their son or daughter and support the next steps of their journey. However, also feeling incredibly protective of their son or daughter and recognising their vulnerability. This seemed to be making it harder for fathers to 'let go'.
- Fathers also seemed to feel torn between recognising that they were responsible for initiating and planning the next steps for the YA, whilst also wanting to avoid thinking about this as this would be a significant shift for the YA and the family.
- Again, fathers seemed to experience guilt in relation to the next steps (e.g., for holding back on aspects of independence, not being able to devote enough time to supporting the next steps, or recognising the autonomy that would typically be given at this age).

Challenges of the wider system around them

- (i.e., challenges with the wider context that the fathers and YA live in, such as, schools local authorities, providers of services, the legal system).
- There was a sense from most fathers that the system was limiting future hopes and prospects for the YA. Fathers described a loss of hope in relation to the education system, options for residential living, and finding suitable avenues for employment.
- Fathers also described needing to fight to get their needs met and experiencing a lack of trust in the system.

Discussion Points

Strengths

- A qualitative methodology was used which provided the opportunity to give fathers a voice.
- Previous research has tended to group together different developmental disabilities (DDs), which risks losing experiences that relate to specific DDs. The present findings hope to be more specific to the population recruited.
- The fathers were recruited from different locations across the UK, and therefore the results are not only representative of one pool of fathers who may access the same services or support systems.

Limitations

- Due to the sample size, it is not possible to generalise the results .
- The inclusion criteria did not stipulate gender, and it is possible that there are differences between parenting male/ female YAs with DS.
- All fathers self-reported to be 'white', 'white/British' or 'White/Caucasian' and appeared to be from relatively middle-class backgrounds. It would be useful for future research to explore experiences of fathers from a variety of backgrounds to ensure we can gain a more detailed picture of fathers' experiences and that any additional support needs or recommendations are captured.

Clinical Implications

- Hearing fathers in the current study speak about their son or daughter highlights the potential that can be achieved for a YA with DS. It is important that these positive experiences of parenting are captured to provide hope and optimism for these families.
- Despite fathers describing many positive interactions and experiences with their son or daughter, the results do also support previous findings that the transition to young adulthood can be a challenging time. It is concerning to reflect on the extent to which fathers' experiences appear to be exacerbated due to the current system and provisions available for the YA. The findings highlight how the limited availability of appropriate supported accommodation, employment opportunities and facilities post-education place increased responsibility and pressure on fathers and families of YAs with DS. This highlights the need for providers of health and social care and relevant stakeholders to consider increasing the funding that is going into providing such services for this population. In addition, for services to consider whether they can offer respite care to families during this time – recognising that for other parents, the responsibility may have decreased, whereas for fathers and families of YAs with DS, the responsibility is amplified once the young person leaves the education system.

Clinical Implications Continued

- The findings also highlighted how difficult these fathers described the process of ‘letting go.’ This indicates that it is important for services to work with families and try to engage fathers to better understand how they can be supported at this time given this non-normative transition. It may be helpful if relevant services engage the family in an extended transition process that facilitates discussion around ‘the next steps’, as well as providing an opportunity for fathers to develop the trust and relationships with services that currently seems to be lacking. Fathers may also benefit from a forum to discuss and ask questions about how to facilitate this process where the transition is non-normative. Trying to support this process will be key, not just for the fathers, but also to support the YA to ensure that families are not inadvertently holding back on the YA’s independence due to their own worries and uncertainties of the future.
- In speaking to these fathers, it seemed as though many did not seem to know or speak to other fathers who were in a similar situation. Fathers may also benefit from more informal options of support, such as a support group for dads to connect with other fathers who also parent a YA with DS. This could provide a space for fathers to share some of their experiences (if they wanted), provide support, and perhaps share knowledge and ideas during this process.
- Fathers’ experiences of accessing and interacting with services highlighted the additional barriers that fathers face in trying to get the YA’s needs met. This is another concern, firstly for the parents engaging in this process, and the time and energy that appears to be needed to secure funding or access to services. Secondly, for the YAs who do not have a parent or guardian who is equipped with the skills, knowledge, or perseverance to secure the opportunities to enable them to have a full and meaningful life. Relevant services may want to consider the accessibility and ease of the current processes in place.

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