THE HOPES AND DREAMS FOR YOUTH WITH INTELLECTUAL DISABILITIES

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ABSTRACT

Transition is difficult for everyone, but it is particularly challenging for youth with ID and their families. When these youth transition out of school to post school environments, they will move from a structured environment with clear daily routines, with school personnel who are tasked to teach and support them, to environments where on-going support and services are not readily available. The purpose of this study is to explore how the various stakeholders envision the future for youth with ID from the perspectives of the individuals themselves, their parents and siblings, and the school personnel. Thirty-three participants from four stakeholder groups (i.e., eight students with ID, 10 parents, six siblings and nine school personnel) participated in this study. The eight student participants were from three special schools. We utilized semi-structured interviews and qualitative research methods to explore the perspectives of stakeholders on youth with ID transitioning to adulthood. All interviews were audio-recorded and transcribed verbatim. The data were analyzed using thematic analysis. The various stakeholders envisioned a future where the youth with ID will: (a) be meaningfully occupied and/or gainful employed, (b) be independent in managing themselves, (c) be emotionally and/or physically healthy, (d) be safe, and (e) have social lives. The findings provide insights into the stakeholders' vision of the future for youth with ID and suggest that while working to increase post school options is critical, more importantly, we need to support the family to empower the youth to explore the available opportunities. A family's hopes and dreams for the youth with ID are often clouded by society's expectations for people with disabilities. Therefore, the mindsets, beliefs and attitudes of the general public towards the participation of people with disabilities in the society must change.

Keywords: Transition, Adulthood, Intellectual Disabilities, School-to-Work

INTRODUCTION

Transition is difficult for everyone, but it is particularly challenging for youth with disabilities and their families. When these youth transition out of school to post school environments, they will move from a structured environment with clear daily routines, with school personnel who are tasked to teach and support them, to environments where on-going support and services are not readily available. Some of these youth with disabilities enter work environments that can be impersonal and most of them face barriers to accessing accommodations and supports at the workplace (Jetha et al., 2019). Many of them will find difficulty forming social networks as an adult and feel isolated in the community (Amado et al., 2013). Many youth with disabilities leave school with no employment in the near future (Nord et al., 2013) and to further complicate matters, there may be limited places at alternative day activity centres for them (Enabling Masterplan, 2022). These youth with disabilities may be inactive, socially isolated, and will continue to rely on family for any social and community interaction (Acharya et al., 2017; Gorter et al., 2014; Ow & Lang, 2000).

As the African proverb says "It takes a village to raise a child"; similarly, it also takes a village to raise a child with disability to adulthood. Many people are involved closely in the transition of youth with disabilities to adulthood. These stakeholders would include the youth with disabilities themselves, their families (e.g., parents, siblings, extended family members), community members (e.g., neighbours, religious leaders), school personnel (e.g., teachers, school leaders, job coaches) and local agencies (e.g., job support coordinators, mental health workers).

Whitney-Thomas and Hanley-Maxwell (1996) surveyed 93 parents of students with disabilities and 111 parents of students without disabilities on their experiences as their children prepare to leave high school. Fourteen of the 93 parents had a child with ID. They found that parents held a complex vision of their children's future, which included the home leaving process, employment, building social relationships, and increased independence. In comparison with parents of students without disabilities, parents of students with disabilities expressed greater levels of discomfort and pessimism in their visions of their child's future.

Blue-Banning and colleagues (2002) conducted focus group interviews with 38 Hispanic parents of youth with ID and developmental disabilities (DD) on their visions for the future for their child with disabilities. The parents had diverse hopes and expectations for their child with disabilities but five themes emerged. Some of the more common themes were employment, daily living skills, and future living arrangement. Other less commonly discussed themes were leisure activities and acceptance by the community.

Another study on parental expectations and hopes for their child's future looked at the experiences of 10 Korean American parents with children with disabilities (Kim et al., 2007). One interesting finding that emerged from this study was that a majority of the Korean American parents had considered group home as a living arrangement for their child with disabilities. The researchers posited that parents' expectations for the child with disabilities appeared to be tampered by society's expectations for individuals with disabilities based on the severity of the disability.

Purpose of Study

The purpose of this study is to explore how the various stakeholders envision the future for youth with ID from the perspectives of the individuals themselves, their parents and siblings, and the school personnel who support these individuals during these important years of preparation to move on to adulthood.

METHODOLOGY

Participants

Recruitment for the study was conducted using purposeful sampling (Patton, 2014). We selected eight youth with ID as the student participants. We approached three special schools for students with ID that have been selected by the Singapore Ministry of Education for the prototyping of the School-to-Work (S2W) transition programme (Ministry of Education, 2014). A student was selected if he/she is: (a) 17-21 years old, (b) diagnosed with ID, and (c) undergoing the selection process for the S2W transition programme. Key informants in this study were the students with ID, their parents, siblings (i.e., if they have a sibling, and the sibling was 14 years or older), and school personnel (i.e., teachers and job coaches). A total of 33 participants from four stakeholder groups (i.e., eight students, 10 parents, six siblings and nine school personnel) were selected to represent diverse perspectives of individuals who were involved in the transition of youth with ID to adulthood (see Table 1 for the demographic information of the participants).

Table 1: Demographic information of participants

Students	Age; Gender; Diagnosis; Ethnicity	Family participants, Age	Family system; Socio-economic status	School participants; Age; Gender
Gamma School				
Aini	17; Female; ID; Malay	(1) Mother, 45; and (2) Elder sister, 18.	Nuclear stepfamily; Low SES	(1) Teacher; 34; Female; and (2) Job coach; 28; Female.
Ben	18; Male; Down Syndrome; Chinese	(1) Father, 49; (2) Mother, 51; and (3) Elder sister, 22.	Nuclear family; Middle SES	
Kappa School				
Chris	18; Male; ID; Chinese	(1) Father, 40.	Single-parent; Low SES	(1) Teacher; 48; Male; (2) Teacher; 29; Female; (3) Teacher; 23; Female; and (4) Teacher; 38; Female.
Dinah	18; Female; ID; Malay-Indian	(1) Father, 51; (2) Mother, 49; and (3) Elder brother, 23.	Nuclear family; Low SES	
Evelyn	18; Female; GDD; Chinese	(1) Mother, 65; and (2) Elder sister, 28.	Nuclear family; Middle SES	
Freddy	18; Male; ID; Chinese	(1) Father, 48; and (2) Younger brother, 16.	Nuclear family; Low SES	
Sigma School				
Gina	18; Female; ID; Filipino	(1) Mother, 51; and (2) Elder sister; 19.	Nuclear family; Middle SES	(1) Teacher; 35; Female;

Students	Age; Gender; Diagnosis; Ethnicity	Family participants, Age	Family system; Socio-economic status	School participants; Age; Gender
Harold	18; Male; Down Syndrome; Chinese	(1) Mother, 55.	Nuclear family; Middle SES	(2) Job coach; 26; Female; and (3) Job coach; 25; Female.

Notes: ID = Intellectual disabilities. GDD = Global developmental disabilities. SES = Socioeconomic status

Research Design

In this study, we used qualitative research methods to conduct an in-depth examination of the perspectives of stakeholders on youth with ID transitioning to adulthood in Singapore. The stakeholders in this study were the students with ID, their parents, siblings and the school personnel who were actively supporting the transition of the students with ID.

Data Collection

We utilized semi-structured interviews in this study. Interviews followed a topical interview guide (Patton, 2014). Interview questions were first distributed to the participants before the interview. All interviews were audio-recorded. The interviewers consisted of the principal investigator, the two co-principal investigators, and a research assistant.

Individual interviews with parents, siblings and school personnel. One-on-one interviews were conducted with parents, siblings, and school personnel at a time and location that was convenient to them. All interviews with school personnel took place in the school. As a semi-structured interview were used, in addition to the interview questions, additional prompting or clarification questions were asked to gain better understanding of the participants' responses. The duration of interviews ranged from 42 to 147 minutes.

Individual interviews with the student with ID. Two initial meetings were scheduled to build rapport between the researchers and the students from each school before individual interviews commenced. As semi-structured interviews were used, the interviewers used additional prompting and clarification questions to help the students with ID. There were three interviews scheduled with each student, staggered across two months. After each interview, the research team summarized the main themes of the interview. The main themes were shared to the students with ID during the next interview session. This procedure allowed the student to provide additional input and served as a reminder of what has been discussed in the previous session. The duration of interviews ranged from 10 to 60 minutes.

Data Analysis

The audio-recorded interviews were transcribed verbatim. The verbatim transcripts were analyzed using thematic analysis. The research team developed the codes by reading through several transcripts and then developing code labels and definitions. Once the code has been defined, the research team members independently identify salient segments in the transcripts. The research team then gained consensus about the meaning of the data, and organized and

categorized the data into emerging themes (Creswell, 2018). Continual peer debriefing and data auditing took place to reduce individual bias and ensured consistency throughout the data analysis process. The researchers undertook two strategies to enhance the rigor of the qualitative research methodological process and to verify trustworthiness (Brantlinger et al., 2005). Multiple informants (i.e., students with ID, parents, siblings, and school personnel) were involved in this study. Member checks were conducted by sharing short summaries of data analysis and interpretations with participants to validate researchers' conclusions.

FINDINGS

How do the stakeholders envision the future of youth with ID who are preparing to leave school?

The data analysis resulted in five key themes in the stakeholders' vision for the students with ID. The key themes on hopes and dreams were further categorized to subthemes within each key theme (see Table 2).

Table 2: Hopes and Dreams: Key Themes and Subthemes

Key Themes	Subthemes
A. Work	A1. The youth will be meaningfully occupied. A2. The youth will be gainfully employed.
B. Independence	
C. Wellbeing	C1. The youth will be happy and healthy. C2. The youth will participate in leisure activities.
D. Personal safety	D1. The youth will be able to protect own self. D2. Others would not harm the youth.
E. Relationship	E1. The youth will spend time with friends. E2. The youth may get married.

Key Theme A: Work. Theme A is defined by the subthemes that relate to how the stakeholders envision the student with ID is going to spend the majority of his or her time once the student leaves school. For most typical adults, this time would be spent either at work or further education. The understanding is that work could be paid or unpaid (e.g., homemaker's unpaid work at home, voluntary services).

Subtheme A1: The youth will be meaningfully occupied. This subtheme illustrates the vision of the student spending his or her time on work or activities that are meaningful. Many parents and siblings shared this sentiment that what was important was that the student spends time doing something that would keep him or her happy. This work could be part-time, voluntary work, or time spent on activities that the student enjoys. One parent said: *Not so much as a job to earn a living, more to socialize, for him (student with ID) to pass his time, to be productive and to contribute to society. Doing something, rather than just sit at home and look at the four walls.*

Subtheme A2: The youth will be gainfully employed. This subtheme describes the vision of the student being gainfully employed. While some family participants alluded to gainful employment as their hope for the student, they also noted that they were not referring to employment that is sufficient for financial independence. All the school personnel were clear that

their hope was for the student to sustain in gainful employment. One teacher stated: *I would want to see my students being able to sustain a job. For the high functioning ones, if possible, I would want them to be a supervisor in a department. But for the low functioning ones, probably just being able to sustain a job, earn a living to support themselves and their family.*

Key Theme B: Independence. Theme B describes a vision of the youth with ID being independent in managing themselves. Almost all the family participants used the term "independence" to describe their hopes and dreams for the students. However, the level of independence that they were referring to differs. Some family participants emphasized that they do not expect that the students will ever be fully independent. Evelyn's mother hoped that Evelyn will be able manage her own basic self-care. She added that a big step for Evelyn will be for her to sleep soundly through the night without disturbing the family. Evelyn's sister hoped that as Evelyn grows older, the family will stop treating her like a kid, and with that Evelyn may grow up differently. Another area of independence for the students is in managing their own behaviour. Ben's older sister said: "He needs to learn to mind his own business and be less picky about other people's behaviour."

Surprisingly, more than half of school personnel did not speak about independence when describing their hopes and dreams for the students. Perhaps within the school setting, the students are expected to be, and have demonstrated that they can be, independent in the school routines. Lastly, several family members and school personnel envisioned that the students will gain better verbal expressive skills so they can voice their opinions.

Key Theme C: Wellbeing. Theme C is defined by subthemes that relate to the wellbeing of the youth with ID. The stakeholders hoped that the students will be emotionally and/or physically healthy in adulthood.

Subtheme C1: The youth will be happy and healthy. This subtheme describes the stakeholders vision of the students being happy and healthy. The majority of the stakeholders hoped that the student will be happy and healthy. Some school personnel used phrases like "realize his true capabilities", "better quality of life", and "live life to the fullest", when describing their hopes and dreams for the students.

Subtheme C2: The youth will participate in leisure activities. The subtheme illustrates the vision of the students participating in leisure activities and being physically active. In this category, the siblings' views stood out from the parents. While several parents mentioned that they hoped that their child will be engage in activities that he or she enjoys, all the sibling participants envisioned that their sibling with ID participating in leisure activities in their adult life.

Key Theme D: Personal safety. Theme D is defined by subthemes that relate to the personal safety of the youth with ID in the workplace and the community. Some stakeholders envisioned that the students will be safe in their adult life.

Subtheme D1: The youth will be able to protect own self. This subtheme explores the vision of the students with ID gaining skills required to be safe or to avoid unsafe situations. Some parents hoped that the student will know how to protect himself or herself, or that he or she will not mix with people who might influence them negatively.

Subtheme D2: Others would not harm the youth. This subtheme alludes to the hope of a life where the student with ID will not be scolded, bullied or taken advantage of by others in the

workplace and the community. Some stakeholders hoped that the student will be able to work and live in a safe environment.

Key Theme E: Relationship. Theme E is defined by subthemes that relate to social relationships that students with ID will have with others. Many stakeholders envisioned that the students will have social lives with friends, and some stakeholders raised the hope of a potential marriage for the student.

Subtheme E1: Friendships. This subtheme discussed the vision of the student with ID having friends that she or he could spend time with. A majority of the stakeholders envisioned the students having friends that they could socialize with. Some stakeholders described an ideal life where the students would work during the week and spend time with friends during the weekend.

Subtheme E2: Marriage. This subtheme explores the vision of the youth with ID developing an exclusive relationship that may lead to marriage. Although some parents envisioned a romantic social life for their child, they were fearful that their child would be taken advantage of. Aini's mother said: "I think one of these days, I have to let her have a social life. But hopefully by that time, she already knows what danger is." Two parents brought up their hope of their child with ID getting married in the future, but the reasons for the marriage were different. Dinah's father hoped that Dinah would get married so that she would be loved and taken care of. Dinah's father elaborated that he would then be at peace as there would be another protector for Dinah. Harold's mother brought up marriage as a possibility for Harold as it would offer him companionship as well as being a natural part of adulthood. Gina's mother, on the other hand, felt strongly that a boy-girl relationship was not an option for Gina. The other parents did not bring up the subject of marriage. Most of the siblings hoped that their sibling with ID will have a girlfriend or boyfriend as an adult, except for Gina's sister who held the same belief as her mother.

Findings from the Interviews with the Students with ID

Outcomes from the rapport building sessions with the students with ID indicated that they had difficulties in answering open questions that did not have or lead to specific topics. The students were not able to lead their answers to specific topics on their own. When the questions were divided into specific topics, they were able to answer the questions. With topic specific questions, the students were able to indicate what they wanted and how they felt about those topics. The students were interviewed on topics about their past school and work experiences, current routines, and future hopes and dreams.

Aini was a friendly girl who was eager to chat with the interviewer. Aini was able to answer most of the interview questions, but she lacked some vocabulary to converse fluently in English. She used some Malay words and gestures to answer some of the questions. Aini also had questions related to boy-girl relationships that she asked the interviewer. Ben was a chatty boy with a vivid imagination. This was reflected in his answers regarding his current friends which included some famous pop stars, and in his answers regarding his future work in which he described the way a police officer would go undercover to capture criminals. Chris was a nonchalant teenage boy who was not keen to answer the interview questions. He did, however, revealed his wish to move to the United States and had many questions for the interviewer regarding the United States. Dinah was a friendly chatty girl who held conversations like an older lady, asking questions like, "Have you eaten?" and "Are you married?" Evelyn, like Aini, was eager to chat with the interviewer and she was able to answer the interview questions. Gina was an

amiable girl who tended to provide brief answers to the interview questions. Freddy and Harold had speech and communication difficulties. Freddy was able to answer the questions after the interviewers provided him additional time and encouragement. Harold's speech was unclear. We included Harold's teacher during his interviews but she too was unable to decipher most of his speech. Thus, Harold's audio recordings were not transcribed.

Overall, the students knew they were leaving school, but they did not seem to have a clear understanding of the future that is ahead of them. Some students had questions for the researchers, which provided a glimpse into the things that mattered to them. The student interviews provided the researchers with a better understanding of the students and provided a context to interpret the findings from the other stakeholders.

DISCUSSIONS

There are few research studies in the area of transition to adulthood for students with disabilities in Singapore. This study attempts to fill a significant research gap in the field of special education. The findings provide insights into the families' vision of the future for youth with ID. The lack of post school options for youth with ID in the area of employment, further education, and meaningful community participation is a challenge, not just in Singapore, but in other developed nations too. Nevertheless, the findings suggest that while working to increase post school options is critical, more importantly, we need to support the family to empower the youth with ID to explore the available opportunities. In the fast-paced and densely populated island city-state of Singapore, independent mobility and open employment can be challenging for youth with ID. The issue of personal safety is a paramount concern for the families. Thus, there is a need to explore innovative ways, perhaps through the use of technology, to enable safe independent traveling for youth with ID.

Limitations and Future Research

The findings should be interpreted with the following potential limitations in mind. First, the generality of the findings to the wider population of youth with ID is limited due to the small sample size and the diversity of cognitive and functioning abilities amongst youth with ID. Only eight families (i.e., eight students with ID, ten parents, and six siblings) and nine school personnel from three special schools participated in this study. Second, when the study commenced, the student participants were still at the special schools, and they were participating in the selection process for the S2W transition programme. For the family participants, the S2W transition programme provided a sense of certainty of a post school placement for the student with ID after he or she leaves school, at least for the immediate future. Furthermore, the students have yet to fully enter a life beyond the special schools, so the family participants' hopes and dreams for the youth with ID reflect their perspectives at this current point of the transition to adulthood. The families' perspectives on these issues may change when the youth with ID enter into the different stages of adulthood.

Conclusion

The purpose of this study is to explore how the various stakeholders envision the future for youth with ID. Unlike the school age years where special schools offer special education services, and a safe haven for students with ID, there exist however, insufficient work opportunities and support services for adults with ID. This hinders the development of a strategic transition plan for life after school where clear goals and delineated services could be outlined. Ultimately, for the transition to a meaningful and inclusive adult life for youth with ID, we need to work closely with the families. A family's hopes and dreams for the youth with ID are often clouded by society's expectations for people with disabilities. Therefore, the mindset, beliefs and attitudes of the general public towards the participation of people with disabilities in society must change.

Acknowledgements

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