PARENT’S EXPERIENCE OF EMPLOYMENT ISSUES FACED BY YOUNG ADULT WITH AUTISM SPECTRUM DISORDER (ASD)

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Presentation Outline

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Introduction

Unemployment among Young Adults (YAs) with Autism Spectrum Disorder (ASD) has become a worrying trend internationally and is an even more alarming trend in Malaysia.

Presently, there is no available statistical data on the employment of individuals with ASD in Malaysia due to the absence of ASD sub-categories in the National Registry of Persons with Disabilities.

Nevertheless, parents of this sub-category have been facing financial struggles and emotional challenges due to their children`s employability issues.

However, to date their concerns have not been made known and unconvincing.
Literature Review

- Previous literatures reported that YAs with ASD had the lowest rate of participation in employment than PWDs of other categories. (Harmuth et al., 2018, Hendricks, 2018, Bush & Tesse 2017, Taylor, Hanninger & Mailllick., 2015).

- Most young adult with ASD continue to live at home with their parent after finished high school. (Smith & Anderson, 2013)

- Lack of resources for adult with ASD is a significant shortcoming in the existing provision of services thus lead to unemployment. (Joanna, 2015)

- Limited cognitive ability was found to be a strong personal factor as prediction of unemployment among YA with ASD. (Shattuck et al., 2012)
Literature Review

- It is reported that good social and environmental support linked to better employment outcome for this group. (Scott et al., 2018)
- Family background and parent’s expectation are the identified predictors that might influence outcome for adolescent with ASD in the transition to adulthood. (Shattuck et al., 2012)
- Parents expressed that their children were not given the opportunities to explore their option and working environment as many of them didn’t get a chance for hands-on working experiences. (Griffiths et al., 2016)
Problem Statement

At present, there is no data available on the prevalence of autism in Malaysia and those who were employed (Neik et al., 2014).

No differentiated employment guideline or training for specific disabilities like ASD.

The lack of ethnic and cultural diversity in autism research may hinder other possible factors associated with unemployment for ASD.
Problem Statement

Most of the decisions made about the child's future were fully reliant on the parents with very little interference from the health care practitioner (Smith & Anderson, 2014).

OT services in Malaysia appear to be underrated in the planning and transitioning from school to adulthood.

At present, the outcome presented in the previous research are mostly analyzed quantitatively.
The aim of this study, therefore to bridge the gap by describing in depth the employment challenges faced by YAs with ASD from parent`s perspectives.

Considerably, the novelty of this study is to reveal the unseen challenges, and to make known the unspoken desires of parents towards employment of their adult children with ASD.
To explore factors associated with employment issues faced by YAs with ASD.

To investigate parental attitudes and expectations towards their child’s employment.
Methodology

Research design: Qualitative, Phenomenological approach

Study Location
IKBN Sepang, Dusun Tua Kolej Kemahiran Tinggi Mara Rembau, Petaling Jaya
Job Coach Supported Employment Programme, Social Welfare

Respondents
8 parents of YAs with Autism Spectrum Disorder (ASD)

Interview
Semi-Structured In Depth Interview
Digitally recorded (approx. 30 minutes to 1 hour)
Transcribed Verbatim
All interviews were conducted at Klang Valley, Johor Bharu, and Seremban, Negeri Sembilan.
**Inclusion Criteria**

Parents of YAs with ASD who complied with the following criteria:-

- aged between 20-35 years old
- been diagnosed with mild ASD by registered medical practitioner
- had completed vocational and job training programme
- had received and completed special education services from public and private recognized by Ministry of Education (MOE)
- was currently unemployed for more than 1 year after finishing the programme.
Sampling Method

Data Saturation
The data collection ceased at eight respondents when saturation is achieved.

Purposeful Sampling method
The researcher also used the snowball sampling to recruit more respondents.
Data Collection Procedure

1. Ethical Approval from ethic committee at University Level
2. Respondents reached and screened via phone calls
3. 8 met Inclusion criteria (4 decline to participate)
4. Consent form, information sheet and The Family Information Questionnaire given to the respondents before interview.
5. Face to face in depth interview conducted (30-60 minutes), interview digitally recorded, transcript verbatim

Guided Permission from community college, National Youth Institute Supported Employment Programme
Data collection took place in two months ‘and a half time frame, with most interviews happening on the weekend at time and place that is convenient for them.
Data Analysis
(6 steps of Thematic Analysis by Braun & Clarke 2001)

Step 1: Getting Familiar with the data
Step 2: Generating Initial Codes
Step 3: Searching for themes
Step 4: Reviewing Themes
Step 5: Defining Themes
Step 6: Writing Up
Demographic Data (Parents)

- **Marriage Status**
  - 75% Married (6)
  - 25% Single Parent (2)

- **Relationship w/child**
  - 87.5% Mother (7)
  - 12.5% Father (1)

- **Edu Level**
  - 50% SPM
  - 25% Diploma
  - 12.5% PhD
  - 12.5% Degree

Parents aged between 44-65 years old
Race: Malay (n=5), Chinese (n=2), Indian (n=1)
### Demographic Data (YAs with ASD)

#### Gender Distribution
- **Female**: 25% (2 YAs)
- **Male**: 75% (6 YAs)

#### Employment History
- **R1**: None
- **R2**: None
- **R3**: Employed less than 3 months
- **R4**: Employed less than 6 months
- **R5**: None
- **R6**: None
- **R7**: None
- **R8**: Employed for one week

#### Educational Background
- **R1**: SPM
- **R2**: Basic Culinary Certification
- **R3**: Basic Food Processing Certification
- **R4**: Basic IT Certification
- **R5**: IGCSE
- **R6**: Animation Course
- **R7**: SPM
- **R8**: IT Certification

### Demographic Details
- **Age**: Ranged between 22-29 years old
- **Level of severity**: Mild to moderate/High Functioning Autism

There is no solid confirmation on the current level of severity of these YAs with ASD as the symptoms may change over time, becoming more or less severe.
THEME 1: Peculiar traits of the YAs with ASD

Subthemes 1: Decreased Executive Function
“He can’t make rational decision and that is mostly based on his own judgement which is sometimes we know is not right” (P8)

Subthemes 2: Social Communication Difficulties
“He has trouble to organize his thoughts and put it into words. He has difficulty to describe and recall previous situation verbally. So, I don’t have confident to let him out for work” (P5)

Subthemes 1: Restrictive & Rigid Behaviour
“She doesn’t like to be told what to do. She always wants everything to be her way” (P3)
THEME 2: Social Contextual and Environmental Challenges

Subthemes 1: Lack of transition planning and career guidance
“He can do animation and graphic design on his computer but as for me finding the place for him to work is the most challenging. After he finished his college, it all goes back to the parents” (P6)

Subthemes 2: Inadequate resources and lack of inclusivity
“At that time, there were not many services available. I’ve sent him to NASOM which is the only Autism Centre that I’ve known that offers vocational training for people with ASD.” (P1)

Subthemes 3: Negative attitudes of employers and public
“He tends to be paid very minimal and sometimes the organizer even asked for free show. Just because he is special doesn’t mean that everything is charity’ (P2)
Subthemes 1: Parent’s persistent fear and worry

“I’m afraid that he got bullied at the workplace. Being ASD and knowing his condition is like that I don’t think he can survive in open employment. What if something goes wrong there?” (P6)

I'm worried and I don't dare to let her go to work by herself. With public transport and all, I don't think she will be safe. Being a girl with special needs, I’m afraid people will take advantage of her.” (P4)

Subthemes 2: Parent’s hope and expectation

“I personally feel that people like my son will never compete with typical work demands, and it’s not fair if they need to compete with normal individuals. I prefer him to work in supported working environment” (P2)
Thematic Map

Peculiar traits of the YAs with ASD

Social Contextual and Environmental Challenges

Overprotective Parent
Discussion

YAs with ASD need to be trained in the development social-communication aspects and independent living skills.

Executive Function (EF) contributes to the likelihood of successful employment for this group.

Active involvement of OTs be instituted as indispensable team members of supported employment mechanism.
Discussion

Parent`s constant fear

- Lead to parent`s preferences that child`s should be employed in familiar environment
- Influence decision making
- Address contextual isolation faced by YA`s with ASD.

Parent`s Empowerment and Advocacy

- Parent`s empowerment program or training facilitate successful employment for YA with ASD.

Parent`s social network

- Parent`s social network associated with the broader assess of employment related services provision and vocational placement.
Conclusion

Employment requirements should take the YAs with ASD abilities, life and employable skills, parents' expectations, employers’ awareness and acceptance, and the socioecology into account.

Parent advocacy may play an important role in Inclusive policy and practice for the betterment of YAs with ASD in Malaysia.

Supported work model of competitive employment was recommended for individual with ASD.
Limitation

- The presence of ID and level of adaptive functioning were not thoroughly screened.
- Rely primarily on parent's report on level of adaptive functioning of their YAs with ASD.
- Lack of diversity in geographic background of the participants.
Recommendation

Exploring the experiences and perspectives of the YAs with ASD themselves and not confined to third parties like parents and employers.

Outline the level of severity of ASD and comorbid mental health difficulties as these two variables may suggest different findings.

Involve a wider audience and consider cultural contexts and viewpoints as diverse as possible.
REFERENCES


INTERVIEW GUIDE

1. Could you tell me about yourself and your child with ASD? Prompts: could you tell me more about it?

2. What do you feel about her/his capability to work? Can you give more examples?

3. Could you share with me about your experiences in regards with your child employment? Prompts: Have she/he ever been employed? How long he/she has been employed/what type of work she/he’s been doing /type of employment/

4. What are the employment issues faced by your child that hinders his ability to participate in the working environment? Prompts: Would you explain that further? Can you give examples? Reason of unemployment

5. What is the important and value of employment of your ASD child to you? Prompts: How this is meaningful to you?

6. What is your view in regards to your child future and employment now?

7. What goals do you have for your child in term of employment? Prompts: What are some barriers that might prevent him/her from achieving this goal?

8. Is there anything more you would like to share about your experiences that I have not asked?
Thank you