

## UNDERSTANDING THE INTELLECTUAL DISABILITY AND PARENTAL EXPECTATIONS

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### ABSTRACT

*This study aims to describe the understanding and expectations of parents towards children with Intellectual Disability (ID). Children with ID have advantages, they have the potential to win, even at the level of world championships, such as the Special Olympics. However, there are still parents of children with ID who do not know their child's potential. They still wonder about what they can expect from children with ID. In addition, although parents of children with ID help their children in therapy, there are still some of them who do not fully understand the concept of ID. To find out aspects of understanding and expectations of parents of children with ID, the researchers conducted interviews with four parents (mothers) of children with ID. Researchers explored the understanding of parents (mothers) regarding what they know about the concept of ID. In addition, researchers also explored their expectations for their children with ID. This research used two questionnaires, namely the Parent's Understanding of ID Scale and the Parental Expectations on ID Scale. The Parent's Understanding of ID Scale consists of 50 items, while the Parental Expectations on ID Scale consist of 10 items. These two scales were developed by researchers based on various literatures. Based on the interviews related to understanding ID, the results obtained: (a) parents stated that they lack information about ID, (b) parents began to know that their children have ID when their children were unable to speak at the age of 12 months, and (c) parents were told by doctor that if the child is unable to walk until the age of 18 months, it is one of the signs that the child has ID. Regarding the expectations toward children with ID, the results show that parents expect: (a) their children will not experience bullying in the community, (b) their children will easily find schools that are suitable for ID, and (c) parents can accompany their children, especially if they are outside.*

**Keywords:** Intellectual disability, parents of children with ID, understanding ID, expectation, special olympics Indonesia

### 1. PREFACE

A family starts with two people, and will have a different experience during the birth of a child. A healthy child is an expectation. But it may be that the child is born not as expected, such as when the child has intellectual disability. The birth and development of a child with disability can cause changes in family conditions (Eracar in). The presence of a child with ID affects the family socially, emotionally, economically, and psychologically (Mukherjee & Shignapure in). Most parents who have children with ID have concerns about the future of their children. They are disturbed by social perspectives on disability, by potential financial problems, by their inability to make sufficient time for their other children. In essence, the presence of children with ID affects the ability of parents to care for their children who do not have ID (Bharvad in).

Around 1-3% of the world population have intellectual disability (ID), or around 200,000,000 people in the world. ID is significantly present in low-income countries or there are 16.41 of every 1,000 people. The United Nations estimated that 80% of all persons with disability live in low-income countries. All over the world, for every ten people, one of them is a person with a disability. Likewise, for every five poorest people in the world, one of them is a person with a disability. Data from the Central Statistics Agency in 2006 showed that around 1-3% of Indonesia's population

are people with ID, whereas in 2015, Retno Astoeti Aryanto, the Chairman of the Board of Trustees of the Asih Budi Foundation, informed that the number of people with ID in Indonesia reached 2.75% out of 280 million people or the equivalent of 7.7 million people.

To recognize ID in general, there are four levels, namely: Mild ID, Moderate ID, Severe ID, and Profound ID.

### **Mild ID**

Individuals with mild ID currently make up the largest number of those diagnosed as having ID. In the world of education, people in this group are considered literate, and their ID level when they reach adulthood is equivalent to that of children aged 8 to 11 years. They generally do not show signs of brain pathology or other physical anomalies, but they often require supervision because of their very limited ability to predict the consequences of their actions. With early diagnosis, parental assistance, and special education programs, most individuals with mild ID can adapt socially. They can master simple academic and work skills, and can become independent citizens (Maclean in).

### **Moderate ID**

Individuals with moderate ID tend to fall into the category of education trainingable, namely that they are considered capable of mastering certain routine skills in everyday life. For examples cooking or light house cleaning work, such as washing dishes. In their daily life, they need to be given special instructions for these activities. For those who reach adulthood, individuals with moderate ID generally reach an intellectual level equivalent to that of children aged 4 to 7 years. Although there are some who can be taught to read and write, only a few are successful in achieving a reasonable mastery of spoken language. Their learning ability is also slow, and their level of understanding of concepts is very limited. They usually appear timid, and they have physical deformities and have poor motor coordination. Some individuals with moderate ID are hostile and aggressive. But generally, they are very friendly and not threatening. In general, with early diagnosis and parental assistance, as well as adequate opportunities for training, most individuals with moderate ID can achieve independence for daily self-care. Their behavior is acceptable and economic survival in the family or environment must be protected by the people around them.

### **Severe ID**

Individuals with severe levels of ID experience very lagging motor and speech development. They have limited self-care and self-help skills, but they will always depend on others for self-care matters. However, there are ways to some extent from training that enable them to perform simple job tasks under the supervision of others.

### **Profound ID**

Generally, individuals with very heavy IDs, are severely deficient in adaptive behavior and are incapable of mastering anything including even the simplest of tasks. To speak is by no means perfect. Has severe physical disability, central nervous system pathology, and stunted growth. Other typical such as convulsions, muteness, deafness, and other physical abnormalities are also common. Such people must remain in care for the rest of their lives. They have poor health and low immunity to various diseases and have a short life expectancy. These very severe cases of ID can usually be easily diagnosed in infancy because of the obvious physical abnormalities, very delayed development (eg, in eating solids), and other symptoms of the disorder. These people have an overall decline in intellectual functioning.

Each family member often has to continuously provide invaluable support throughout their life for family members with ID (Chou et al. in). Family is the most important factor in the life of persons with disabilities because of the perception of disability itself. The role assigned to persons with disabilities is strongly influenced by the family structure and the place where the person lives in a family (Rao in).

Mother as a family member is the most important figure in the life of a person with ID. There are some mothers who may not find it difficult to raise their children. However, most mothers who have concern for the future of their children will experience significant changes in family life and social relationships. Most children with ID who live at home with their parents will be provided with lifelong support from their parents (Emerson & Hatton in). This support may include direct care i.e. assisting with activities of daily living, such as washing or dressing. Provided emotional care that is providing support and encouragement. Provided mediation treatment, for example negotiating with others on behalf of the individual, and services and managing finances (Horowitz in).

Parents still have expectations with the ID conditions of various levels described above. Expectations are beliefs about what might happen in the future. Expectations come from individual beliefs, personal experiences and through experiences in social life. Expectations are influenced by social interactions with individuals and organizations, as well as legal and cultural values.

West et al. in explores parents' expectations of teachers and schools showing that parents expect quality of teaching, academic progress, their children's happiness, homework, discipline, and that their children receive fair information.

Doren et al. examined the expectations of parents of their children with ID whether it affects the results achieved. Their findings show that parental expectations predict outcomes, but the type of disability affects between parental expectations and outcomes (Doren in). Newman's study also found that parental expectations differ by type of disability, with parents of children with learning difficulties having higher expectations than parents of children with ID, autism, or other disabilities (Newman in ). Rutchick et al. specifically investigated parental expectations regarding education for children with behavior problems.

Many parents of people with ID have hopes that their children can participate and even excel in sports activities. Harada et al. stated that "little is known about exercise in the lives of people with ID". Sports activities can actually provide opportunities for ID children.

Sports and games make major contributions to the evaluation of human development. Sport is often regarded as something out of date, even though there are now many studies that prove that exercise is beneficial for children, adolescents, adults, and the elderly. Physical health, emotional well-being, friendships, and self-esteem are all positively affected through sport participation. However, these benefits and opportunities are rarely used by people with ID.

Athletes with ID can participate in various international sports competitions. One of the options of those with the highest sporting achievements and with the highest intellectual capacities is to engage in competitive matches regulated according to the rules of elite sport. Where the main goal is to participate in an event that really values people with ID. Any ID person can participate in

international sporting events and become champions by committing to the Special Olympics (SO) movement.

In this study, the researcher intends to examine how parents perceive ID and what their expectations are for their children with ID. This research can be used for the purposes of the Special Olympics Indonesia (SOIna), parents, or education administrators for children with ID.

## 2. RESEARCH METHOD

### Participants

Participants in this research are mothers whose children are actively practicing at SOIna and had participated in international and local championships. The number of participants is 4 mothers whose children excel at SOIna, both winners at the international level and still at the local (Indonesian) level, and each is represented by a boy and a girl. These four participants are domiciled in Jakarta, where the selection is not limited by religion, race, ethnicity, age, economic status, and marital status.

### Research Instrument

In this study using a sampling technique, namely purposive sampling. Whereas for research design using mixed methods, case studies, and test-retest.

This research used two questionnaires, namely the Parent's Understanding of ID Scale and the Parental Expectations on ID Scale. Each of these scales is described by the researchers in the following paragraph.

#### *Parent's Understanding of ID Scale*

This scale consists of 50 items developed by the researchers based on various literatures. Examples of the items on this scale are: "Some of the most common ID signs are .....", "The common cause of ID is .....", or "ID has a deficit of function in .....". Participants were asked to choose one of the most correct answers among four alternative answers. The test-retest reliability coefficient of this scale is 0.88.

#### *Parental Expectations on ID Scale*

This scale consists of 10 items, compiled by the researchers, based on a literature. This scale has three dimensions (a) academic skills (are academic skills consisting of writing, arithmetic, and other school assignments), (b) social skills (are social skills that are used daily to interact and communicate with others), and (c) life skills (are life skills used to describe a basic set of skills acquired through learning in everyday life). An example of an academic skill dimension item: "Children with ID can read general signs/instructions". An example of a social dimension item: "Children with ID can obey their parents' orders". An example of life skill dimension item: "Children with ID can have math skills in everyday life". The test-retest reliability coefficient of this scale is 0.77.

Participants were asked to fill out an informed consent as a sign of their willingness to participate in the research process from beginning to end.

### 3. RESULT AND DISCUSSION

In the description of understanding ID of parents can be described quantitatively and qualitatively. Quantitatively, parents' understanding of ID can be categorized with the criteria of "high" (> 75% correct answers), "sufficient" (50-75% correct answers), and "low" (if the correct answers are below 50%).

**Table 1**

*Parent's Understanding of ID*

| No. | Participant | Assessment | Intervention | General | Criteria %         |
|-----|-------------|------------|--------------|---------|--------------------|
| 1   | A           | 65.21      | 50           | 77.77   | 64.32 (Sufficient) |
| 2   | B           | 56.52      | 63.88        | 88.88   | 69.76 (Sufficient) |
| 3   | C           | 76.08      | 49.99        | 61.10   | 62.39 (Sufficient) |
| 4   | D           | 43.47      | 38.88        | 83.32   | 55.22 (Low)        |

The description of the understanding ID of parents is as follows: (1) participant A with 64.32% "sufficient" criteria; (2) participant B with 69.76 "sufficient" criteria; (3) participant C with 62.39% "sufficient" criteria; and (4) participant D with 55.22% "low" criteria.

Based on further analysis, the following are conditions that make parents (mothers) understand/realize that children's conditions are not the same as children in general (allegedly to have ID). The explanation above can be seen in Table 2 below.

**Table 2**

*Parents' Understanding When Knowing the Condition of Children as People with ID*

| No. | Understanding Points   | Participant(s) |
|-----|--|----------------|
| 1   | Doctor did not inform the actual conditions at birth.                  | A, D           |
| 2   | No speech ability at the age of 12 months.                             | A, C           |
| 3   | No walking ability at the age of 18 months.                            | A              |
| 4   | Check for chromosomes at the age of 24 months.                         | A              |
| 5   | Child did not get examined since birth because they do not understand. | A, D           |
| 6   | Lack of information about ID.  | A, C, D        |
| 7   | Delivery of information about ID at first seemed less polite.          | A, D           |
| 8   | Felt the treatment of ID was late.                                     | A, C, D        |

Related to the description of parental expectations on children with ID is as follows. The criteria above a scale of 4 are "high", a scale of 3 – 4 are "sufficient", and below a scale of 3 are "low".

**Table 3**

*Parental Expectations on Children with ID*

| No. | Participant | Academic Skill | Social Skill | Life Skill | Scale Criteria of 1 - 5 |
|-----|-------------|----------------|--------------|------------|-------------------------|
| 1   | A           | 3.5            | 3.75         | 3.9        | 3.71<br>Sufficient      |
| 2   | B           | 3.5            | 5            | 4.6        | 4.36<br>High            |
| 3   | C           | 3.16           | 4            | 3.1        | 3.42<br>Sufficient      |
| 4   | D           | 3.16           | 5            | 4.6        | 4.25<br>High            |

**Table 4***Parental Expectations on Children with ID (Academic Skill Dimension)*

| Item No. | Parental Expectations on Children with ID | Scale 1 - 5 |
|----------|---|-------------|
| 1        | Reading general signs / instructions      | 3.62        |
| 2        | Read books / tasks at school              | 3.50        |
| 3        | Do math problems at school                | 2.87        |

**Table 5***Parental Expectations on Children with ID (Social Skill Dimension)*

| Item No. | Parental Expectations on Children with ID | Scale 1 - 5 |
|----------|---|-------------|
| 8        | Obey parents' orders                      | 4.50        |
| 9        | Interact with other people                | 4.37        |

**Table 6***Parental Expectations on Children with ID (Life Skill Dimension)*

| Item No. | Parental Expectations on Children with ID | Scale 1 - 5 |
|----------|---|-------------|
| 4        | Applying mathematics in everyday life     | 3.25        |
| 5        | Practice hygiene on self                  | 4.25        |
| 6        | Dress up by themselves                    | 4.12        |
| 7        | Attempt to eat by themselves              | 4.37        |
| 10       | Protect self                              | 4.25        |

ID conditions in young children are often overlooked by doctors. Findings alone or as part of a broader syndrome or disorder may occur in 2-3% of the population. Genetic and environmental factors are some of the causes of ID. Doctors cannot determine the etiology despite thorough evaluation in at least 30-50% of cases. A comprehensive personal and family medical history is critical to the diagnosis, where there is a complete physical examination and a careful assessment of the child's development. The provision of genetic counseling is based on appropriate evaluation and referrals, so that resources in the family understand how to carry out early intervention programs for children. Regular follow-up visits from the family physician are encouraged to facilitate a smooth transition from adolescence to young adulthood. This statement supports the findings above on the point that doctors do not inform the actual conditions at birth.

Among the major developmental problems of parents are cognitive delays, particularly delays in language and adaptive functioning. Both are hallmarks of ID, or, if language is specifically affected, language impairment. This statement supports the findings above on the point of no speech ability at the age of 12 months. Whereas approximately 25% of cases are due to chromosomal or metabolic abnormalities which support the statement of chromosomal examination at the age of 24 months.

Being late to walk independently after the age of 16 months is one of the markers of child development. The World Health Organization (WHO) states that 97% of boys and girls start walking before 16 months of age, and 95% of children walk between 9-16 months. The achievement of gross motor milestones such as independent walking has been identified as being influenced by prenatal, perinatal, and postnatal environmental factors. The pending process and ID is a consistently identified relationship. Clinical reports of delayed walking in children who were subsequently diagnosed with ID were the first studies to hypothesize a negative linear relationship between walking age and IQ. This statement supports the findings above on the point of no walking ability at the age of 18 months.

Good adaptation from parents will get social support. From various directions you will find: spouses, siblings, family members, friends, therapists, and the school. While in the family, you will get support from your home or husband, support from other close family members and support from other children. There are some couples who actively contribute to childcare and work within the home, and some who provide emotional support to caregivers, as well as take care of financial responsibilities. Siblings are expected to contribute by sharing parenting, working at home, and supporting parents emotionally. Don't forget the contributions of grandparents, uncles and aunts who proved to be a major source of support. This statement supports the findings above on the point of needing assistance the home, expecting not to be bullied in the community, and not easy to have a child with ID. Schools are the main place to socialize with the wider community for people with ID. Discrimination still occurs in schools that run inclusive programs, this supports the statement that it is not easy to find schools suitable for ID.

In the lives of people with ID, higher levels of social support are positively correlated with higher quality of life. While low is negatively correlated with depression (Lunsky & Benson; Meins; Reiss & Benson in). This statement supports the findings above on the point that children were not examined from birth because they did not understand, lack of information, about ID, delivering information about ID at first seemed impolite, and late treatment of ID.

Informal support is one factor that seems to make a difference in helping families of persons with disabilities make positive adjustments. It is very important to have support from your partner. The division of tasks within the family which has formal and informal support outside the family seems to cope well (Trivette & Dunst in). Some of the programs planned for parents of children with ID could include: (a) helping all children to understand and connect with children who have different abilities, (b) helping parents teach their children how they should respond to ridicules or comments about their disability, (c) helping parents know what and how much to expect from their child's academic and social progress, (d) helping parents to develop strategies to advocate for the optimal education of their children, (e) helping parents know and when to foster independence in children with disabilities (Hendrick in).

The following are guidelines for all educators of ID children from an early age: (a) support parents of children with disabilities; (b) provide information to parents on how to foster the development of their children with disabilities; (c) provide follow-up assistance to bring program activities at home; (d) refer parents to support groups or other parents whose children have similar disability; (e) inform parents of their legal rights; (f) inform parents of available community resources for them and help them access services; (g) identify the needs related to disability of siblings and other family members; (h) provide information about the prevention of disability for younger siblings; and (i) build parental trust and skills development for children with special needs.

Although adaptive abilities in ID children develop far below their age, this is needed to help individuals interact in their environment. Language ability, namely the ability to speak in a social sense is one of the adaptive abilities. Storytelling for language development is one of the methods and approaches for how language can develop. This storytelling method is recommended for children from Participants A – C – D and children with an equivalent level of ID and have difficulties in conveying speech communication.

#### 4. CONCLUSIONS AND RECOMMENDATIONS

There are three conclusions, namely (a) there is a sufficient picture of understanding ID from parents; (b) there is a sufficient picture of parental expectations of children with ID; and (c) there is a sufficient role in understanding ID and parental expectations of winning children in SOIna.

Theoretical suggestion is that the results of this study will contribute to the science of educational psychology, especially the understanding of ID and expectations of parents who have children with ID, also useful for similar research.

At the time of interview, it should be done face-to-face so that facial expressions and reactions can be seen when answering questions, because in the study only one person met face-to-face with Participant A at their home with a health protocol. Meanwhile, two participants were willing to do video call namely participant D, and participant C with WhatsApp call because it was more comfortable without looking at their face. Finally, participant B did not wish to be interviewed, so they only sent a short answer via WhatsApp, where previously a list of questions had been sent.

It is also recommended in future studies to look for children of equal birth age, considering that in this study, children who won international competitions had entered young adult stage and children who won local competitions were still in their early teens.

ABA interventions that are useful for minimizing the symptoms of behavior disorders can be suggested. ABA intervention is a treatment approach that can be applied as early as possible, preferably before the age of three, which is in accordance with the principles of ABC (Antecedents, Behavior, and Consequences).

In the future, there should also be further research on fathers whose children have ID, or research on mothers who have successfully overcome acceptance of their children with ID.

Practical suggestions are for: (a) parents who have children with ID especially in SOIna; (b) teachers / trainers / administrators who handle children with ID; (c) the school, especially school for special children; (d) large families with ID children; and (e) the surrounding community (inner circle) in which there are children with ID in their environment.

On this occasion the researchers are very aware that this research would be better if the interviews were conducted more than once, so that the required information could be more in-depth and focused.

With the warmth and support of professionals, families, and friends, many parents of children with ID, it is hoped that they will begin to focus on their child's strengths and achievements.

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