

## Down Syndrome : Through The Eyes of The Parents

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### Abstrak

Sindroma Down merupakan salah satu kejadian kelainan kromosom tipe aneuploidi yang kerap ditemukan. Kejadian Sindroma Down terkait erat dengan disabilitas intelektual dan stigma sosial yang melekat padanya. Pandangan orang tua mengenai Sindroma Down yang tercerminkan melalui perilaku amat penting karena dukungan keluarga merupakan salah satu kunci utama untuk mengoptimalkan kualitas hidup penyandang Sindroma Down. Studi ini merupakan studi deskriptif pada orang tua penyandang Sindroma Down yang bersekolah di Sekolah Luar Biasa (SLB) di Palembang. Perilaku orang tua diukur dengan menggunakan kuesioner HealthStyles©. Sebagian besar orang tua penyandang Sindroma Down sepakat bahwa anak dengan Sindroma Down harus bersekolah di SLB (82,5%) karena mayoritas meyakini pencampuran penyandang Sindroma Down di sekolah biasa dapat mengganggu murid lain (60%). Namun orang tua memiliki pandangan optimis bahwa anak penyandang Sindroma Down dapat bekerja jika telah dewasa (72,5%). Mereka pun percaya bahwa penyandang Sindroma Down tidak lebih rentan mengalami kecelakaan kerja di tempat kerja (37,5%). Dari studi ini terlihat bahwa orang tua penyandang Sindroma Down memiliki perilaku yang bervariasi tergantung dari aspek mana mereka memandang Sindroma Down.

Kata kunci : Sindroma Down, Perilaku, Orang Tua

### Abstract

Down syndrome is one of the most common chromosomal aneuploidy related to intellectual disability and social stigma. Insight from parents towards Down syndrome that is reflected by their attitudes are pivotal since supportive family is one of the key in optimizing Down syndrome patient's quality of life. This is an observational descriptive study towards parents with Down Syndrome children in Special Need School in Palembang. Parents' attitudes toward Down Syndrome were assessed by using a self-filled questionnaire that was used in a HealthStyles© survey previously. Majority of the parents agreed that Down Syndrome children should go to a special school (82.5%) because many of them believe that including students with Down Syndrome in classes with typically developing students is distracting (60%). However, as many as 72.5% parents believe that Down Syndrome kids should be able to work when they grow up, because 37.5% stated that persons with Down Syndrome in the workplace do not increase chance for work accidents. It is showed that parents still hold a mixed attitudes toward their children. When it comes to educational aspects, majority of them hold somewhat a negative attitudes. Yet when it comes to dependency, most of them are optimistic about their children's chance to work.

**Keywords:** *Down Syndrome, Attitude, Parents.*

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## 1. Introduction

As one of the most common chromosomal disorders, the incidence of Down Syndrome varied worldwide. It is believed to reach 1 in 1000 to 1 in 100 births worldwide.<sup>1</sup> Down syndrome itself is a condition where a person have extra copy of chromosome 21.<sup>1</sup> It is resulted in intellectual disability, and other clinical manifestations.<sup>2</sup> Life expectation wise, people with Down Syndrome actually can live long enough like normal people as long as the health issues like heart problems are being well taken care of. Growing old, people with Down Syndrome also face some health issues. Some of them could develop Alzheimer, although the severity differs from one to another.<sup>3</sup> All these health problems they are suffering could lead to the decrease of their quality of life.

How others see the disease and the way people react to those who suffered from it is pivotal to help improve their quality of life. It is showed in previous study that perception of Down Syndrome and people's attitudes towards them are important in the inclusion of people with Down Syndrome in the society and supporting families.<sup>4</sup>

There were many studies about attitudes towards Down Syndrome that have been conducted. Some were focusing on specific groups of people like students<sup>5</sup>, teachers<sup>6</sup>, and physicians<sup>7</sup>. Some studies were not specific, where it gathered information about attitudes towards Down Syndrome from society as a whole, where different groups of people were asked to participate in the survey<sup>8,9</sup>.

There is not much survey studies investigating the attitude of parents' who have Down Syndrome children towards Down Syndrome. Previous studies were mostly qualitative studies, and not surveys. There has been no similar study in Indonesia, let alone in Palembang, where attitudes from both specific groups and community towards Down Syndrome have never been assessed before. Parents are the first and foremost caretaker. Their faith, spirit, and optimistic are more

likely to improve their children's quality of life. An insight from parents on how they see and perceive Down Syndrome that reflected on their attitudes towards Down Syndrome could help many comprehend what is there to be done to help the inclusion of people with Down Syndrome in the communities, and how to help their quality of life eventually.

## 2. Methods

This is a cross-sectional study using a questionnaire that was previously used in HealthStyles© survey.<sup>8</sup> This research was conducted in two special need schools in Palembang. Samples were parents of Down Syndrome kids that went to those schools during the study, and willing to participate in the study. There were 40 participants that were involved in this study. Demographic data being obtained were age, sex, marital status, occupation, religion, educational background, and also family history.

The 2008 HealthStyles© questionnaire actually had 207 questions designed to collect basic demographic information as well as information related to health issues, attitudinal variables, and media preferences. Aside from those aspects, this survey also include four items that specifically designed to asses one's attitude towards people with Down Syndrome. These four items were an adaptation from previous surveys<sup>3,10</sup>. In HealthStyles© survey, participants were asked to choose one of five response options on a Likert Scale that was reflecting their level of agreement based on their preferences.

In this study, the options was simplified into only two options: agree and disagree. The first two items being asked were the attitudes toward people with Down Syndrome in Educational settings. While the next two items being asked were the attitudes toward people with Down Syndrome in workplace settings.

### 3. Results

A total of 40 parents from both special need schools were involved in this study. Demographic characteristics of the participants including sex, age, marital status, occupation, educational background, and family history are presented in Table 1 below.

**Table 1. Demographic Characteristics of Participants**

Demographic Characteristics	n	%
<b>Sex</b>		
Male	5	12.5
Female	35	87.5
<b>Age Group</b>		
31-40	19	47.5
41-50	15	37.5
51-60	6	15
<b>Marital Status</b>		
Married	35	87.5
Divorce	1	2.5
Deceased Spouse	4	10
<b>Occupation</b>		
Housewife	30	75
Entrepreneur	6	15
Labour	2	5
Freelancer	1	2.5
Teacher	1	2.5
<b>Religion</b>		
Islam	37	92.5
Budha	2	5
Catholic	1	2.5
<b>Educational Background</b>		
Elementary school	4	10
Junior High School	10	25
Senior High School	21	52.5
Vocational School	2	5
Undergraduate	3	7.5
<b>Family History</b>		
Yes	5	12.5
No	35	87.5

The demographic characteristics of the children can be seen in table 2 below where age and sex of the children are presented.

**Table 2. Demographic Characteristics of The Children**

Demographic Characteristics	n	%
<b>Sex</b>		
Male	26	65
Female	14	35
<b>Age</b>		
7 years old	3	7.5
8 years old	9	22.5
9 years old	5	12.5
10 years old	4	10
11 years old	4	10
12 years old	7	17.5
13 years old	5	12.5
14 years old	3	7.5

Parental attitude towards Down Syndrome was assessed by using the Healthstyles© survey like it can be seen in Table 3 below.

**Table 3. Parental attitudes toward people with Down Syndrome**

Items	Agree	Disagree
Students with Down Syndrome should go to Special Schools, separate from other children	33 (82.5%)	7 (17.5%),
Including students with Down Syndrome in classes with typically developing students is distracting	24 (60%)	16 (40%)
Persons with Down Syndrome in the workplace increase chance for accidents	15 (37.5%)	25 (62.5%)
Most adults with Down Syndrome should be able to work	29 (72.5%)	11 (27.5%)

### 4. Discussion

Most of the participants filling the questionnaire were the mothers (87.5%), since majority of them are housewives (75%). Only five fathers were participating in this study.

Four fathers are an entrepreneur, while one father is a labour. Based on the age group, as many as 19 participants (47.5%) fall into the age range of 31-40 years old. The youngest parent was 31 years old, with the oldest participant was 53 years old. Both are the mothers. As in the educational background, it ranges from elementary school to undergraduate. Yet more than half of the parents were graduated from Senior High School (52.5%). Although almost all the participants are moslem, there were also two parents that are Budhist, and one parent that is Catholic. Aside from all the demographic characteristics being identified, family history of having another family member affected by Down Syndrome was also being asked. As many as five respondents (12.5%) stated that they have a positive family history where there are other family members with Down Syndrome as well. Two respondents said that the uncle is affected by Down Syndrome. Another two stated that the cousin of their children is having Down Syndrome too. Only one participants told that family member that is affected is only a relative she does not know exactly the relationship.

Children with Down Syndrome of which their parents being involved in this study are a student in Special Need Schools in Palembang. The youngest kid was 7 years old and the oldest was 14 years old. Most of them are male (65%) while the rest is female (35%).

Many previous studies that were trying to assess attitudes towards people with Down Syndrome were focusing on the community only. Studies that were investigating about parental attitudes toward their own kids who are affected by Down Syndrome are not commonly found. Let alone a survey study. This study is the first study in Palembang, Indonesia that was assessing parental attitudes towards children with Down Syndrome.

There were four items in the HealthStyles© survey where parents were asked to choose between agree or disagree on each item. Two items are reflecting their attitudes about people with Down Syndrome in

educational settings. While another two are reflecting their attitudes about people with Down Syndrome in workplace settings. The four items being asked can be seen in table 3 below.

Based on the result of the survey, 33 parents (82.5%) believe that students with Down Syndrome, including their children, should go to Special Schools, separated from other children. This reflects a negative attitude toward people with Down Syndrome in Educational settings. Nowadays, there are schools that provide inclusive educational system where typically developing students and children with disability, including intellectual disability like Down Syndrome go to school together. In this type of school, they will mingle, interact, and receive the same lesson from teachers. However, the negative attitudes of parents with Down Syndrome kids are most likely undertandable in Indonesia. It is because inclusive educational system is not widely known in Indonesia, let alone in Palembang. Previous studies also showed that people who have had experienced with people with intellectual disabilities are more likely to be supportive. This somewhat negative attitude that the parents possessed is probably also caused by their belief on including students with typical developing students could distract others kids (60%).

However, when it comes to workplace settings, majority of the parents have a positive attitudes. As many as 29 parents (72.5%) stated that people with Down Syndrome should be able to work. They also believe that people with Down Syndrome will not increase the incidents of accidents in workplace settings (62.5%). This optimistic are very important since parents will most likely encourage their kids to be independent and go to work to provide themselves in the future.

## **5. Conclusion**

Parents with Down Syndrome kids showed a somewhat mixed attitudes toward their children. Majority of them uphold a

relatively negative attitudes regarding educational settings for Down Syndrome kids. However, most of the parents are optimistic about their children's future related to work settings. Future studies trying to identify and analyze factors that affecting parental attitudes is needed.

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