

COMMUNITY PERCEPTIONS OF EARLY ADULT *DOWN SYNDROME* ; A *SYSTEMATIC REVIEW*

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ABSTRACT

Background: society's perception of Down syndrome in early working adults. Objective: to determine the public's perception of Down syndrome in early adulthood. **Method:** the source of the article used was obtained from a search via Google Scholar. A literature search using the same theme contained 17,700 articles and filtering was carried out according to the theme, including 18 articles. Article searches are limited from 2019-2024. After the article is obtained, the article is reviewed until it reaches the stage of creating a systematic review. The keywords used in the article search are " Perception" "Public" "Down syndrome" "Early Adulthood". **Results:** Society's perception of young adults with Down syndrome is often filled with stigma and negative views, including from their own families, which causes social isolation. In addition, they also face discrimination in society and the workplace. However, research shows there is support for reducing this discrimination in the work environment. The rights of people with disabilities, including individuals with Down syndrome, have been regulated in legislation that guarantees employment opportunities and comfort in the workplace. **Conclusion:** Individuals with Down syndrome, from children to adults, are an important part of society. However, they often face stigma and negative views because their physical differences are considered unusual. Community support is important, because they have the same passion for life as other people. To overcome stigma and discrimination, society can expand employment opportunities for them, demonstrating that they are capable of participating like other individuals

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INTRODUCTIONS

Down syndrome (DS) is the most common genetic disorder associated with intellectual disability, it is one of the most complex genetic conditions. (Antonarakis et al., 2020). Physical examination is the most accurate first step in diagnosis, while iron deficiency is common, as in the general population (Bull,

2020). According to the Indonesian Center for Biodiversity and Biotechnology (ICBB) Bogor, more than 300 thousand children in Indonesia suffer from Down syndrome . The global incidence rate is estimated at 8 million. (Fortea dkk., 2020)In terms of mental development, individuals with Down syndrome tend to have moderate to severe intellectual disabilities with distinctive characteristics. (Situmeang et al., 2023).They often experience difficulties in learning and development, as well as in expressing their thoughts and needs (Ayuningrum & Afif, 2020).

People with Down syndrome often face difficulties in adapting to the social environment (Latifah., 2018 dalam Rejeki Ekasasi et al., 2021). Even though they often have significant mental retardation, they are also known to have a good nature, are cheerful, full of affection, able to adapt well in society, and like to joke around. Education for children with Down syndrome aims more at developing social interaction and independence than at improving their intellectual abilities (Ayuningrum & Afif, 2020).

Children with Down syndrome need consistency in learning good behavior. They are often considered "stubborn," a term used to describe resistance or silent disobedience. A social environment that has a positive impact can help children recognize positive emotions in themselves. Social isolation will not help their development, especially for individuals with Down syndrome . The results of therapy carried out on children with Down syndrome show that there are four forms of behavior that can be classified as social behavior and asocial behavior. Social behavior includes friendly behavior, sympathy, cooperation, and competition, while asocial behavior includes resistance and attack(Ayuningrum & Afif, 2020).

Early adulthood is considered a period of search, discovery, and maturation, which is often characterized by emotional problems and tension, social isolation, commitment, as well as changes in values and adjustment to new lifestyles (Putri, 2018). It is important for adolescents with Down syndrome to experience work , post-secondary education, as well as participating in community activities to facilitate their transition to adult life (Hodapp dkk., 2019). Parents play an important role in adjusting and accepting children with Down syndrome through early stimulation, which helps them carry out daily activities independently. Many children with Down syndrome eventually succeed in becoming champions in various fields such as sports, arts, culinary arts, and others (Rejeki Ekasasi dkk., 2021).

However, the talents and skills possessed by most individuals with Down syndrome will not have economic value if they are not managed well by their parents or caregivers , because most of them are not able to manage activities independently. (Rejeki Ekasasi et al., 2021).Their presence requires special attention, both for individual development and their integration in society. John Christen Beck and Martha describe some of the fears in their lives regarding Adam's development. In the article entitled " The Gifts of Down syndrome : Some Thoughts for New Parents ", Martha tells of her experience of living in an isolated world, where some people tend to view individuals with Down syndrome with strangeness and keep their distance, such as when Martha brought 3-year-old Adam year to a meeting on the campus where he studied. They also felt worried that the presence of Adam with Down syndrome would interfere with his older brother's care because of the complexity of the management that had to be carried out with Adam(Balasong., 2022)

From the specific description of Down syndrome which includes developmental delays and obstacles, as well as the fears of parents or families who have children with Down syndrome , it is clear

that stigma and negative perceptions often haunt the lives of individuals with Down syndrome and their families. Physical differences often make individuals with Down syndrome the center of attention in the public environment, either with cynical, condescending or surprised views, because their physical appearance is unique and different from most people (Renawati et al., 2017 dalam Balasong., 2022). The aim of this systematic review is to examine public understanding of Down syndrome in young adults. This review includes both negative and positive views of what individuals with Down syndrome can do , as well as the quality of life they currently experience and their future potential.

RESEARCH METHOD

Database search via Google Scholar with the keyword perception; society: Down syndrome ; early adulthood, to determine the relevance of the articles found. Articles were selected using the criteria of publication year 2019-2024, full text in English and Indonesian. There were 17,700 articles on the same theme found by the researchers and they were filtered through Publish or Perish , which Google Sholar detected as many as 182.3 and produced 200 articles. After the article is obtained, the article is reviewed until it reaches the stage of creating a systematic review. Researchers deleted similar articles, reviewed articles that met the grouping criteria through title and abstract, then examined the research and screening results and found 18 articles that were suitable to continue with discussion.

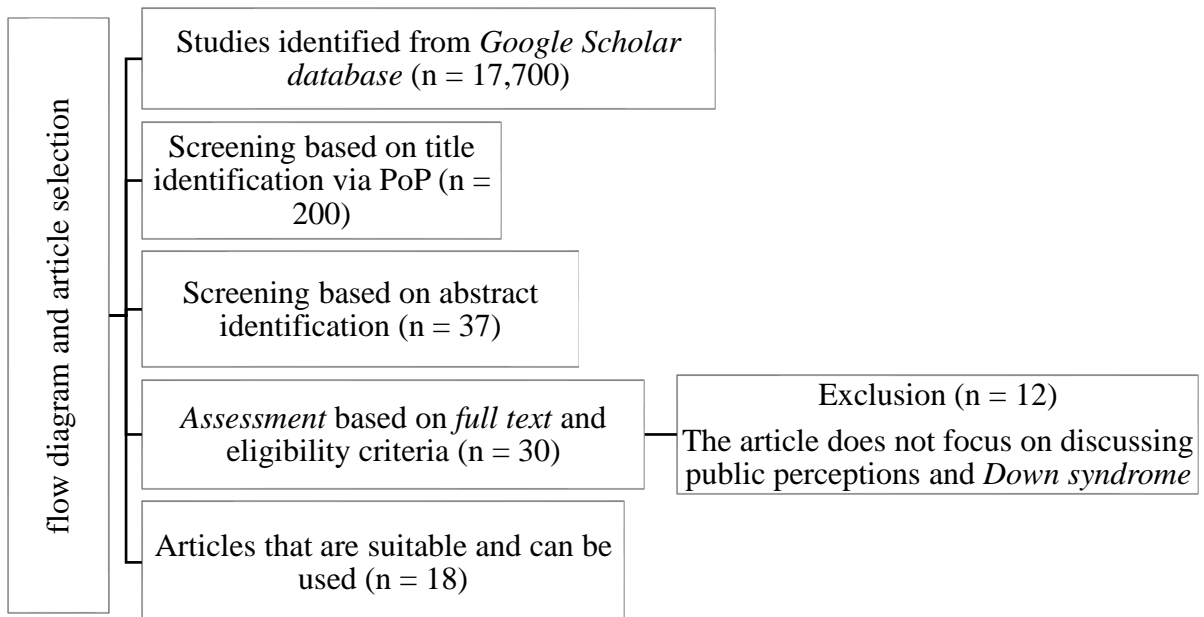


Figure 1. *Flow diagram* and article selection

RESULT AND DISCUSSION

RESULT

A literature search on the same theme found 17,700 articles that matched the keywords. Researchers carried out screening based on the title and then adjusted it to the theme from Publish or Perish, resulting in 200 articles. Selection based on abstracts contained 37 articles. Of the 37 articles, they were selected according to the eligibility criteria and 18 articles were obtained which were then used in the systematic review .

From the 18 articles reviewed, it was found that society's perception of individuals with Down syndrome in early adulthood is often filled with stigma and negative views, even among families or parents who have children with Down syndrome , which often leads to self-isolation in the community. Apart from stigma and bad perceptions, individuals with Down syndrome also face discrimination in society and the workplace. However, several previous studies have shown support for reducing discrimination experienced by individuals with Down syndrome in the work environment. In addition, the rights of people with disabilities, including those with Down syndrome , have been regulated in legislation that guarantees employment opportunities and comfort in the workplace.

Table 1. Summary of literature search results

No	Title	Results
1.	<i>Down syndrome</i>	Understanding of <i>Down syndrome</i> , mouse models of DS, histopathology of Alzheimer's disease, and clinical trials to treat intellectual disability in DS (Antonarakis dkk., 2020).
2.	Understanding Individuals with <i>Down syndrome</i> in the Middle of Society and Religion	A systematic explanation of the physical and non-physical characteristics of individuals with <i>Down syndrome</i> , including intervention and treatment methods, as well as an explanation of their status as non-mukallaf who are not required to carry out sharia worship such as prayer and fasting (Balasong., 2022).
3.	<i>Focus Group Discussion: Parents' Perceptions of Economic Empowerment Efforts for Down Syndrome Children in Yogyakarta</i>	Shows that parents feel anxious about their children's future in terms of meeting their economic needs independently. They hope for a comprehensive and sustainable economic empowerment program (Rejeki Ekasasi dkk., 2021).
4.	Social interaction of children with <i>Down syndrome</i> at Nusa Indah Kindergarten, Jakarta	The four types of behavior seen include social behavior and asocial behavior. Social behavior shown includes friendliness, sympathy, cooperation and competition. Meanwhile, asocial behavior consists of resistance and attack behavior (Ayuningrum & Afif, 2020).



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5. *Down syndrome* Understanding the health problems and life course of individuals with *Down syndrome* is complex, involving a variety of different medical, psychological, and social issues from infancy through adulthood. Individuals with *Down syndrome* and their families generally have a positive attitude and desire to achieve a high quality of life, based on the strengths and skills of the affected child or adult. Published guidelines provide recommendations and standards to help people with *Down syndrome* reach their full potential (Bull, 2020).
 6. *Health issues across adulthood in Down syndrome* The health and longevity of individuals with *Down syndrome*, with longer life spans, is accompanied by aging-related health problems. A survey of five large databases shows that significant changes occurred in the decade of the 50s, with this period characterized by a decline in general health and an increase in the prevalence of certain health conditions. Although the onset of Alzheimer's dementia is the most prominent health condition in the 50s and 60s, other conditions also appear, sometimes along with dementia, sometimes separately (Hodapp dkk., 2019).
 7. *Clinical and marker changes of Alzheimer's disease in adults with Down syndrome* The interpretation of Alzheimer's disease in individuals with *Down syndrome* suggests a long-lasting preclinical phase, in which biomarkers follow a predictable pattern of change for more than two decades. Due to its similarity to the sporadic, autosomal dominant nature of Alzheimer's disease, as well as the high prevalence of *Down syndrome*, this population is considered an appropriate target for preventive treatment of Alzheimer's disease (Fortea dkk., 2020).
 8. The importance of early adults completing their developmental tasks An understanding of the role of guidance and counseling teachers and counselors is to be able to guide clients in improving individual abilities and development, so that clients can achieve and carry out their developmental tasks well (Putri, 2018).
 9. The Importance of the Role of Parenting Styles in the Independence of *Down Syndrome Children* The role of parents in increasing children's independence includes efforts to improve the quality of life of *Down syndrome sufferers* through special therapy and training, which has a
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10. Social and Emotional Impact on Families of Babies with *Down syndrome*

positive effect on the development of communication skills and self-development (Situmeang dkk., 2023).
 11. Empowering People with Disabilities Through Training on Making Pillow Dolls for *Down Syndrome Children* in Panciro Village

Families that have a member with *Down syndrome* experience major social and emotional impacts, including stress, worry, anxiety, sadness, discrimination, and changes in family dynamics (Nanda dkk., 2023).

Encouraging the independence of children with *Down syndrome* through training in making pillow dolls can be a means of increasing their knowledge, skills and economy. By producing various pillow doll characters, they can gain significant benefits (Ananda dkk., 2020).
 12. Expectations of Parents with Children with Special Needs Who Grow Up

Differences in parents' expectations for children with special needs (ABK) aged over and under 15 years include different focuses. Parents who have ABK aged over 15 years tend to have identified their child's potential and are trying to develop that potential so that the child can be independent. They are aware of children's difficulties in attending formal education and try to teach skills that can make children productive. On the other hand, parents with ABK who are teenagers and under 15 years old tend to still focus on developing their children's academic abilities, especially reading and writing, social skills, and the ability to carry out worship independently. These abilities are considered the basis necessary for children to be independent in their lives (Haerani dkk., 2022).
 13. Concept of Community Development Through Inclusive Schools for People with *Down Syndrome*

Recommendations that can be implemented to implement community development programs in the education sector include the establishment of inclusive schools, which aim to create an equitable and fair education scheme (Fadri Z., 2021).
 14. Social Interaction of *Down syndrome Children* with the Family and Community Environment (Case Study of *Down syndrome Children* in All Special

The birth of a child with *Down syndrome* can be caused by factors such as the mother's age at pregnancy, use of drugs during pregnancy, and use of contraceptives. The parenting patterns adopted by families vary depending on their knowledge about *Down syndrome*. Parents and society generally emphasize aspects of independence and communication skills in their parenting patterns (Renaldy. R. S., 2020)
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- Schools in Tasikmalaya City)
15. The Role of Public Relations in Socializing the Pembina Medan State SLB E School in Establishing Relationships with Families of Children with *Down Syndrome* Through Journalistic Media
 Parents who have children with *Down syndrome* often experience rejection or isolation from society, so that many of them lack social interaction in that environment (Fadila & Saragih, 2023).
 16. Various Discrimination of Persons with Physical Disabilities in the World of Work
 People with physical disabilities still often experience discrimination in the work environment, such as stigma, wage gaps, lack of accommodation facilities, difficulty in getting promotions, and difficulty getting insurance. This can hinder their performance at work. The discrimination they experience can cause them to feel psychologically inferior and have difficulty adapting, and even tend to isolate themselves (Mulyani dkk., 2022).
 17. Challenges for Counselors in Optimizing the Performance of Persons with Disabilities to Minimize Acts of Discrimination in the Work Environment
 Counselors have an important role in overcoming problems, creating a more humane work environment, and encouraging the fulfillment of needs such as easier accessibility, improving skills, and providing fair employment opportunities. This can encourage authorities to create laws and regulations that promote equal opportunities for people with disabilities to find work, thereby creating inclusivity and equality in society (Alridho L. M, dkk., 2023).
 18. Guarantees for Persons with Disabilities in Obtaining Work
 Legislation regulating the rights of persons with disabilities in obtaining employment includes adequate aspects. In addition, the government has also issued a series of regulations confirming these guarantees as part of the implementation of the law (Aurelia Marthen & Herning Sitabuana, 2024).
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DISCUSSION

Understanding of Down syndrome includes mouse models of DS, histopathology of Alzheimer's disease, and clinical trials to treat intellectual disability in DS (Antonarakis et al., 2020). A systematic explanation of the physical and non-physical characteristics of individuals with Down syndrome ,

intervention and treatment methods, as well as their status as non-mukallaf who are not required to carry out sharia worship such as prayer and fasting (Balasong, 2022). Parents feel anxious about their children's future in meeting their economic needs independently and hope for a comprehensive and sustainable economic empowerment program (Rejeki Ekasi et al., 2021). The types of behavior seen include social behavior such as friendliness, sympathy, cooperation and competition, as well as asocial behavior such as resistance and attack (Ayuningrum & Afif, 2020).

Understanding the health problems and life course of individuals with Down syndrome is very complex, involving medical, psychological and social problems from infancy to adulthood. Individuals with Down syndrome and their families usually have a positive attitude and desire to achieve a high quality of life, based on their strengths and skills. Published guidelines provide recommendations and standards to help individuals with Down syndrome reach their full potential (Bull, 2020). The health and longevity of individuals with Down syndrome, accompanied by aging-related health problems, underwent significant changes in the decade of the 50s, including an increase in the prevalence of certain health conditions. Alzheimer's dementia becomes the most prominent health condition in the 50s and 60s, although other conditions also appear either along with dementia or separately (Hodapp et al., 2019). Interpretation of Alzheimer's disease in individuals with Down syndrome suggests a long preclinical phase, with biomarkers following a predictable pattern of change for more than two decades, making this population an appropriate target for preventive Alzheimer's treatments (Fortea et al., 2020).

The role of guidance and counseling teachers and counselors is to guide clients in improving individual abilities and development so that they can carry out developmental tasks well (Putri, 2018). Parents have an important role in increasing the independence of children with Down syndrome through special therapy and training, which has a positive impact on the development of communication skills and self-development (Situmeang et al., 2023). Families with Down syndrome face major social and emotional impacts, including stress, worry, anxiety, sadness, discrimination, and changes in family dynamics (Nanda et al., 2023). Pillow doll making training can increase the independence of children with Down syndrome, with benefits in the form of increasing their knowledge, skills and economy through the production of various pillow doll characters (Ananda et al., 2020).

Parents' expectations for children with special needs (ABK) differ based on the child's age. Parents with ABK aged over 15 years tend to focus on developing their children's potential to live independently, being aware of their children's difficulties in formal education, and teaching them productive skills. In contrast, parents with ABK under 15 years of age focus more on developing academic skills such as reading, writing, social skills, and the ability to carry out worship independently, which are considered basic for children's independence (Haerani et al., 2022). Recommendations for community development in the education sector include the establishment of inclusive schools to create an equitable and just education scheme (Fadri Z., 2021). The birth of a child with Down syndrome can be caused by the mother's age at pregnancy, use of drugs during pregnancy, and use of contraceptives. Parenting patterns vary depending on knowledge about Down syndrome, with a focus on independence and communication skills (Renaldy RS, 2020).

Parents with Down syndrome children often experience rejection or isolation from society, so many lack social interaction (Fadila & Saragih, 2023). People with physical disabilities still often face discrimination in the workplace, such as stigma, wage gaps, lack of accommodation facilities, difficulties with promotions, and insurance problems, which hinder their performance and cause psychological problems such as low self-esteem and self-isolation (Mulyani et al., 2022). Counselors play an important role in solving problems, creating a more humane work environment, and encouraging the fulfillment of needs such as accessibility, skill development, and fair employment opportunities. This can encourage the formation of laws and regulations that support equal opportunities for people with disabilities, creating inclusivity and equality in society (Alridho LM, et al., 2023). The law regarding the rights of persons with disabilities in obtaining work already includes adequate aspects, with various government regulations strengthening these guarantees as part of the implementation of the law (Aurelia Marthen & Herning Sitabuana, 2024).

Researchers observed that there is a positive view from society towards individuals with Down syndrome, where they appreciate the individual's ability to carry out daily activities like other people. For example, some individuals with Down syndrome are able to make coffee for their families or work as waiters in a cafe. The community's positive reaction to this ability reflects enthusiasm and appreciation for the perseverance and zest for life possessed by individuals with Down syndrome. In Indonesia, one clear example is "Coffee Shop Kopi Tuli," which is the first coffee shop managed by people with disabilities. This coffee shop is an example of how society can respect and support people with disabilities, showing that they are also capable of carrying out activities like other individuals.

CONCLUSION

Individuals with Down syndrome, from children to adults, are an integral part of society. However, society's perception of them is often filled with stigma and negative views because their physical differences are considered unusual. Community support is very important, because individuals with Down syndrome have the same enthusiasm for life as other people. Understanding, support and appreciation for their enthusiasm and ability to adapt is very necessary. Therefore, to support them and overcome stigma and discrimination, society can expand employment opportunities for individuals with Down syndrome, allowing them to participate in daily activities and showing the world that they can carry out activities like other individuals.

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