

EMPOWERING THE DOWN SYNDROME COMMUNITY

Title: Leave No One Behind

Presented by: FSTEP Batch 26 Trainees Group 1

Date: 11th April 2024

Table of Contents

<u>Executive Summary</u>	1
<u>Problem Statement</u>	1
<u>Project Objectives</u>	1
<u>Potential Solutions</u>	1
Enhancement of Website and Social Media Presence	2
Development of Informative E-Book.....	3
Partnership with Businesses for Inclusive Employment	3
Inclusion Day	3
<u>Data and Research</u>	4
<u>Relevant Stakeholders</u>	4
<u>Estimated Timeline</u>	4
<u>Estimated Budget</u>	4
<u>Conclusion</u>	4

Executive Summary

Individuals with Down syndrome often encounter challenges in performing basic activities independently and accessing meaningful careers despite the unwavering love of their families. This proposal introduces the “Leave No One Behind” initiative, a comprehensive project dedicated to empowering individuals with Down syndrome across Malaysia. This initiative seeks to bridge these gaps and foster a more inclusive and supportive environment that value diversity and promotes equal opportunities.

Problem Statement

- Insufficient awareness and understanding of the Down syndrome (DS) community in Malaysia contribute to limited opportunities and barriers to inclusion, hindering individuals' ability to thrive.
- Difficulties with fine motor skills among individuals with Down syndrome impact their independence and future prospects.
- Individuals with Down Syndrome often face challenges in finding meaningful employment opportunities. Limited job prospects and workplace discrimination can hinder their ability to participate fully in society and achieve financial independence.

Project Objectives

The primary objective of this proposed project is to empower individuals with Down syndrome by implementing targeted initiatives that promote inclusivity, enhance opportunities for independence, and challenge misconceptions surrounding their capabilities. Specifically, the project aims to achieve the following objectives:

- **Raise Awareness:** Develop and implement awareness campaigns to dispel myths and promote understanding of Down syndrome within the community.
- **Promote Inclusive Employment Practices:** Collaborate with local businesses to create inclusive employment opportunities, emphasizing the unique skills and capabilities of individuals with Down syndrome.
- **Promote Social Interaction and Community Engagement:** Foster social interaction and community engagement to cultivate a sense of belonging and acceptance among individuals with Down syndrome.

Potential Solutions

Our initiative aims to empower individuals with Down syndrome through a comprehensive set of solutions designed to enhance awareness, promote inclusive employment practices, and foster social interaction and personal development. Through strategic collaborations and innovative activities, we

seek to create meaningful impacts in the lives of individuals with DS, emphasizing empowerment, skill development, and community engagement.

1. *Enhancement of Website and Social Media Presence*

- Collaborate with Persatuan Sindrom Down Malaysia (PSDM) to improve their website, making it more informative, accessible, and engaging for the public.
- Implement social media strategies to increase PSDM's visibility and outreach, sharing educational content, success stories, and relevant resources.
- Launch a weekly news update series on social media and PSDM's website, covering topics related to Down syndrome, including awareness, support, and debunking myths.
- Create a Telegram group to recruit volunteers to share about their experience with Down syndrome.
- Create e-career guide section regarding the employment opportunities.

2. *Inclusion Day*

- The primary goal of organizing an Inclusion Day is to foster social interaction and create a supportive and engaging environment that encourages personal growth and positive youth development.
- The activities planned are as follows:

Fashion show with Barter System Integration

- Description: Participants will have the chance to select clothing items they desire from curated collection. Rather than traditional purchasing methods, participants will engage in a barter system where they can exchange tokens (representing currency) for the clothing items of their choice. This approach allows participants to experience the principles of trade and exchange in a hands-on and interactive manner. Each participant will be paired with a dedicated trainee who will assist them in navigating the world of fashion.
- Objectives: Provide participants with autonomy and decision-making opportunities and promote communication skills through interaction with volunteers and peers during the barter process.

Squeeze The Sponge

- Description: Participants will be provided with water-soaked sponges of varying sizes. They will engage in squeezing these sponges to release the water into a small pail or bottle.
- Objectives: This activity aims to strengthen hand muscles and improve grip strength, which are essential for various daily tasks such as writing, grasping objects, and etc.

Pick Up the Rubber

- Description: Participants will use the chopsticks to pick up floating rubbers.
- Objectives: This activity aims to improve their fine motor skills and foster patience and concentration while completing the task.

Please note that the activities listed here are for reference purposes and represent a selection of planned events. We will tailor activities to accommodate different age groups, ensuring a diverse and

inclusive experience for all participants. Additional activities will be included to further enrich the program.

Data & Research

The study conducted at the Human Genome Centre, Universiti Sains Malaysia, reviewed cytogenetic data from 4,064 patients referred between 2008 and 2019. The study focused on the prevalence and characteristics of live-born trisomic cases, particularly Down syndrome (trisomy 21), Edwards syndrome (trisomy 18), and Patau syndrome (trisomy 13).

Key findings from the study include:

- Among the referred cases, 25.4% (1,034 cases) were live-born trisomic cases, with Down syndrome (trisomy 21) being the most common type, accounting for 21.1% of live-born trisomic cases.
- Approximately two-thirds of maternal and paternal ages of individuals with Down syndrome were 35 years or older, highlighting advanced parental age as a significant risk factor.

Furthermore, research and data from various sources emphasize the diverse capabilities and opportunities available to individuals with Down syndrome, particularly in terms of living arrangements, education, and employment. Kishore Vellody, MD, medical director of the Down Syndrome Center of Western Pennsylvania, emphasizes that the old notion suggesting individuals with Down syndrome cannot secure a job or live independently no longer holds true. Contrary to past beliefs, many adults with Down syndrome are employed and lead independent lives. They work in various sectors, such as office settings, restaurants, cleaning services, and grocery stores. Moreover, there's a potential for future job opportunities in technology, as many individuals with Down syndrome excel in computer work.

Moreover, inclusive recreational programs like Camp PALS have emerged as powerful catalysts for personal growth, meaningful friendships, and skill development among individuals with Down syndrome. Research findings highlight the positive impact of inclusive camp environments in promoting social inclusion, enhancing life skills, and supporting successful transitions into adulthood.

These insights highlight the evolving understanding of Down syndrome and emphasize the importance of inclusive employment practices and tailored support to maximize independence and integration into various aspects of society.

References:

<https://mjpath.org.my/2022/v44n2/down-syndrome.pdf>

<https://mpaeds.my/journals/index.php/MJPCH/article/view/45>

<https://www.everydayhealth.com/down-syndrome/affects-everyday-living-adulthood/#:~:text=Because%20many%20people%20with%20Down,Vellody%20says.>

https://tigerprints.clemson.edu/cgi/viewcontent.cgi?article=4094&context=all_theses

<https://www.wikiimpact.com/children-first-disability-second-how-children-with-down-syndrome-are-losing-out-in-the-malaysian-education-system/>

<https://apm.net.au/job-seekers/resources/great-job-ideas-for-people-living-with-down-syndro>

<https://fastercapital.com/content/Down-syndrome-support-Empowering-Entrepreneurs--Down-Syndrome-Support-and-Business-Success.html>

<https://story.motherhood.com.my/blog/down-syndrome-support-groups-gives-hope-to-youngsters/>

Relevant Stakeholders

Please refer to the 'Companies' and 'Partners' sheet in the Google Sheet link below for more information on the relevant stakeholders:

<https://docs.google.com/spreadsheets/d/1mv1zIfo3esIPqiWS2NAiQ8PNmUr0WRrwbJcvGM4sqY/edit#gid=1972886433>

Estimated Timeline

Please refer to the 'Project Timeline' sheet in the Google Sheet form below:

<https://docs.google.com/spreadsheets/d/1mv1zIfo3esIPqiWS2NAiQ8PNmUr0WRrwbJcvGM4sqY/edit#gid=264124387>

Estimated Budget

Please refer to the 'Expenses' sheet in the Google Sheet form below:

<https://docs.google.com/spreadsheets/d/1mv1zIfo3esIPqiWS2NAiQ8PNmUr0WRrwbJcvGM4sqY/edit#gid=1580776603>

Conclusion

From the research and data presented, it is evident that individuals with Down syndrome possess remarkable capabilities and potential for growth and independence. Despite past misconceptions and challenges, the evolving understanding of Down syndrome emphasizes the importance of tailored support, inclusive environments, and inclusive employment practices to maximize opportunities for empowerment.

In Malaysia, where outdated statistics indicate that 1 in 800 live births are babies with Down Syndrome, it is clear that there is a significant population of individuals who require ongoing support and advocacy to thrive. Therefore, it is imperative that we do not give up on individuals with Down syndrome. Instead, we must continue to promote awareness and provide the necessary resources to ensure their full integration and participation in society.

By embracing their unique strengths and capabilities, we can foster a more inclusive and supportive community that celebrates diversity and empowers individuals with Down syndrome to thrive. Let us commit ourselves to this mission and work together towards a future where every individual with Down syndrome has the opportunity to achieve their full potential and lead fulfilling lives.