

Envisioning a brighter future for children with special needs



LETTERS

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AS of January 2023, Malaysia had 637,537 registered persons with disabilities under the Social Welfare Department. Of this number, nearly 40% (235,731) fall into the category of learning disabilities.

Not all disabilities are visible or readily noticeable. Learning disabilities are often called “invisible disabilities”, and this significantly affects the educational outcomes and quality of life for children with such disabilities.

Children with special needs often require a tailored education to address their unique requirements. This may involve enrolling in special education programmes, hiring private tutors or therapists, or considering private schooling options that better meet their needs.

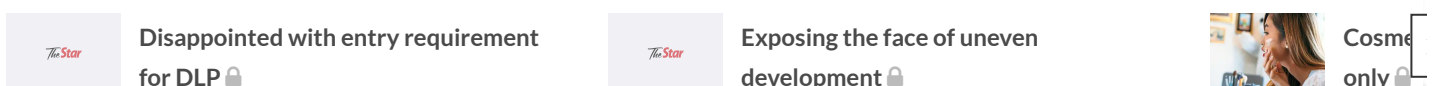
To ensure these children can eventually lead independent lives, parents face considerable financial challenges, leaving them vulnerable to financial insecurity.

The issue is rather simple to understand but challenging to address – when services become scarcer, prices inevitably rise; in essence, as supply decreases and demand increases, costs surge, in line with the economic principle of supply and demand.

Specialised educational services often come at a higher cost than mainstream education. This does not even include the medical expenses associated with frequent doctor visits, medications, surgeries, and assistive devices.

Many children with special needs require assistive devices and technologies to help them navigate daily life and enhance their mobility. These include wheelchairs, hearing aids, communication

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These expenses often escalate over time, especially if the child has complex or chronic medical conditions. Children with comorbidities – two or more concurrent health conditions – also face additional medical expenditures.

Moreover, health insurance or takaful coverage may not fully encompass the treatments required, leaving parents to shoulder a heavy financial burden.

For instance, autistic children often need regular sessions of occupational therapy, speech therapy, and behavioural interventions, which can be very costly. These costs can accumulate rapidly, straining family finances, particularly if insurance or government assistance programmes fall short.

Caring for children with special needs demands significant time and attention, making it challenging for parents to maintain full-time employment or advance in their careers.

Parents may need to reduce their working hours, take unpaid leave, or, in the worst cases, leave their jobs altogether to provide intensive care and support. This can lead to a decline in household income and financial instability.

In addition, some employers may not accommodate flexible schedules, or the time off required by parents of children with special needs, further limiting their employment options.


For example, parents of children with severe physical disabilities may need to be on constant standby to assist with personal care, mobility, and medical needs. These caregiving responsibilities often make it difficult to sustain traditional employment.

Many developed countries have support systems to assist families with children who have special needs, including disability benefits, tax credits, and educational support.


But even these programmes often fall short in covering the wide range of expenses involved in raising a child with special needs. This is due to stringent eligibility criteria, complex application processes, bureaucratic red tape, and long waiting lists for services. Consequently, parents struggle to access the financial resources they need to adequately support their children.

While various incentives are announced annually in Malaysia during budget presentations to target

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For the long term, the government should establish a trust fund for children with special needs in Malaysia, drawing inspiration from Singapore's Special Needs Trust Company (SNTC).

The SNTC runs a Special Needs Savings Scheme that allows families to allocate funds in trust for the long-term care of children with special needs.

Through this scheme, parents can open a trust account in their child's name with regular or lump-sum contributions. These funds are professionally managed to ensure financial growth and stability, and can only be used for the child's needs, such as care, education, or medical expenses.

This ensures that individuals with special needs have access to dedicated savings to meet their requirements throughout their lives, including after their parents or guardians pass away.

By establishing such a trust fund, families can safeguard the financial well-being of their loved ones with special needs, ensuring continued care and support throughout their lives.

This initiative aligns with the aspirations of the Madani economy, emphasising social justice, public welfare, and the creation of an inclusive society. By providing financial security to families of children with special needs, the nation can strengthen its social safety net and build a more sustainable and prosperous future for all.

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