

5 major gaps in services for children with disabilities

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THIS is an open letter to the education and health ministers and Social Welfare Department officers to outline key gaps in our services for children with disabilities.

The National Early Childhood Intervention Council (NECIC) is a registered coalition of parents, therapists and professionals from a large number of civil society organisations and agencies working with and advocating for children with special needs.

We recognise that the new government has many challenges and that many proposals have been put forward for change. So much so that, at times, it may be difficult to see the forest for the trees.

We would like to outline five key failures in our services for children with disabilities and how we can overcome them. If these key areas are not addressed, we will continue with the current poor service provision for these children and their families.

Education Ministry: limited inclusive education for all children

Recommendations:

- 1. The Special Education Unit should be changed to Inclusive Education Unit
- 2. Implement a national shadow aide programme

Our National Education Blueprint fully supports inclusive education (the NECIC helped provide input into the NEB).

However, a majority of children with special needs and their families are facing difficulty and resistance when they try to ask for inclusion.

The ministry provides data suggesting that inclusion is improving but much of this is integration, not inclusion.

Children with special education needs are still segregated in classes despite many having abilities to do well in mainstream education. We will never reach the National Education Blueprint (NEB) target of 75% inclusion by 2025 if we continue in this way.

The key change required is to transform the Unit Pendidikan Khas to Unit Pendidikan Inclusive to reflect the NEB.

This will change the entire focus of the department and teachers on the ground. As long as we are focused on "pendidikan khas" we will never be inclusive.

We should aim to shut down all pendidikan khas classes and special education teachers should be supporting mainstream teachers.

Second, we need sufficient numbers of well-trained teachers and resource personnel to aid and educate children with special needs in mainstream education classes.

We urgently require a shadow aide programme to support teachers. The ministry has not put this vital resource in place and parents who try to make available the provision are often hindered by local authorities. This is a major way forwards to enable inclusion.

Health Ministry: limited service provision for children with disabilities

Recommendations:

3. Engage medical universities to improve curriculum on special needs

4. Decentralise care – meet the disability needs of rural communities

It is a reality that most doctors who qualify do not know what to do with children with disabilities. Most have received very limited training in their undergraduate days on understanding children with special needs and their families, being able to do an assessment and plan management.

It is vital that we equip doctors with the necessary skills, as 15% of all children have disabilities. The ministry must serve as a pressure group with the Education Ministry to engage local medical universities to improve their training curriculum on special needs.

An addition concern is that most services for children with disabilities are concentrated in urban settings.

The rural community is grossly underserved and poorly reached. There is a need to bring professional services to these communities rather than demand that they be forced to travel to urban centres, further exacerbating their burdens and depleting limited resources. Our regional hospitals have many specialists and therapists, it is time to make it a policy for them to spend time and serve in the community.

Welfare Department: limited service delivery

Recommendation:

5. Upgrade and transform all rural EIP services to provide quality care

All children with special needs require early intervention programmes (EIP). This is crucial if they are going to discover their potential and be able to resource education and employment training.

Most of the quality EIP training and programmes are provided by civil society groups, most of which are urban-based.

The rural communities are served by community-based resource centres. These centres are under the care of the Welfare Department.

These centres play a vital role but a majority provide limited care. Unlike urban-run EIPs, which provide staff training and quality EIP service provision, these centres are stagnant and end up just functioning as "day-care" services.

There is an urgent need to provide quality EIP services in rural, underserved communities. The ministries and department need to work together to make this happen.

Inclusion of children with special needs into kindergarten and preschool services must be a vital part of this plan. The NECIC has formal training modules for staff working in EIP and preschool inclusion and are happy to support the training of staff.

The National Early Childhood Intervention Council appeals to the ministers and department to please make real the rights and needs of 15% of our population who are often neglected. If these five key initiatives are not put in place, we will continue to fail these children and their families.

Please do not let the dreams of any child with disability fail because we did not offer them a chance to realise them. – August 29, 2018.

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* This is the opinion of the writer or publication and does not necessarily represent the views of The Malaysian Insight.