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# Special Education in the United Kingdom: A Case Study of a WHS- Child Mawaddah at Ash-Field Academy Leicester

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Abstract: This paper presents the parents' observation on the special education provision to Mawaddah, a child with a rare genetic disorder Wolf Hirschhorn Syndrome (WHS) that causes multiple disabilities and global development delay to her. During her stay in the UK in year 2015- 2017, Mawaddah was enrolled to Ash-Field Academy in Year 1 and 2. The council-funded school was comprehensively equipped with the necessary facilities and equipment and attended by highly trained teachers to meet the educational needs of the special children. Immediately after her enrolment, Mawaddah underwent various assessments to determine her educational and healthcare needs. Subsequently, an Education, Health and Care Plan (EHCP) was proposed for Mawaddah that outlined the expected outcomes from Mawaddah's learning process, the approaches and interventions in teaching, the facilities and equipment required, as well as the relevant parties responsible for the provision of educational and health care needs and other support such as the school transportation service. Overall, the parents' opined that this was an example of a success story of highly accessible and top quality special education in the United Kingdom. The reasons behind this success are mainly the integrated system between the National Health Services (NHS), the Department for Education (DfE) and the local authorities, a clearly spelled-out guidelines and codes of practice to cater to the educational needs of special children, and the incredible commitment from relevant parties responsible for the provision of educational, health and care needs of such children. To conclude, the policy and infrastructure for education and healthcare support for special children in the UK were absolutely state of the art, indicating a highly accessible and top quality special education in the country. Policymakers in Malaysia could learn so much from the UK in crafting the special education policies in line with the Malaysia Education Blueprint 2013-2025.

Keywords: Wolf-Hirschhorn Syndrome, special education, developed country, Ash-Field Academy, Leicester

# INTRODUCTION

Education has long been recognized as a human rights and equality issue. Children with disabilities are entitled to right to education as stated various articles of United Nation declaration such as in the Sub Article 1, Article 26 in Universal Declaration of Human Rights (UN, 1948), Article 13 of International Covenant of Economic, Social and Cultural Rights (UN, 1966), Article 28 of Convention of the Rights of the Child (UN, 1989), and Article 7 and Article 24 of Convention on the Rights of Persons with Disabilities (UN, 2006).

Meanwhile, special education in the UK is provided for children with moderate of severe learning difficulties such as hearing, speech, sight impediment, with a physical disability or autism, or with a behavioral problem which prevent or hinder them from attending a mainstream school for their age group (Special Education in the UK, 2019).



In the UK, the National Health Services (NHS) via its Special Educational Needs and Disability (SEND) Code of Practice (SEND, 2014) and Children and Families Act (2104) would provide guidance to relevant authorities in health and social care, education and local authorities to make sure the children and young people with SEND were properly supported. Born in the UK in 2009, Mawaddah is a special child and her healthcare and educational needs during her stay in the UK would have been under the responsibility of the NHS.

#### **Background Of Mawaddah**

Mawaddah was born on 4th December 2009 in Leicester, United Kingdom whilst the father was studying for his PhD at the University of Leicester. Mawaddah's birthweight was only 1.8 kg and immediately after birth, a doctor took a blood sample from her for a genetic test.

After a month, Dr Andrew Currie, Consultant Neonatologist at Leicester Royal Infirmary informed the parents that Mawaddah was diagnosed with a genetic disorder called Wolf-Hirschhorn Syndrome (WHS) or 4-p deletion. This syndrome was due to deletion in some parts of the p-arm of the fourth chromosome and it was later classified as "de-novo" (non-hereditary).

This syndrome had caused global development delay to Mawaddah's physical and mental growth. She had had epilepsy episodes with different frequency and severity, although currently she has been fits-free for more than four years since 2015. She also has non-symptomatic atrial septal defect (ASD), and at 45-day age she had underwent a repair surgery for her congenital diaphragmatic hernia.

Since she was born in the UK, Mawaddah had benefited greatly from the comprehensive healthcare system of NHS. After the WHS diagnosis, Mawaddah was immediately sent for necessary scans such as the scans for her internal organs and spinal structure, as well as the MRI, EEG, and ECG scans. She was also sent for hearing and vision tests.

She also received the necessary intervention support such as the physiotherapy, occupational therapy, speech therapy, and home visits by play-specialist. She was also prescribed high-calories milk to accelerate her physical growth. As for her epilepsy, she was under close monitoring by the community pediatrician and neurologist and was prescribed the required medication for epilepsy control. These were all provided free of charge to her since Mawaddah and her family were legally in the UK due to her father's status as a student.

In January 2012, the family returned for good to Malaysia after her father's PhD study had completed. Mawaddah's healthcare follow-ups were continued at Hospital Sultanah Bahiyah Alor Setar, Hospital Jitra and Hospital Pulau Pinang, Since 2013, Mawaddah has been attending Pusat Pemulihan Dalam Komuniti (Community-Based Rehabilitation Centre, PDK) at Jitra. Mawaddah also goes to see private occupational and speech therapists during the weekends.

In August 2015, 6-year old Mawaddah and her family returned to the UK for her father's postdoctoral study and they stayed in Leicester for two years until July 2017. Not long after the family's arrival in Leicester, they were visited by Early Support key-workers whom they had known during their first stay in the UK. In the second visit by the key-workers, a representative from Ash-Field Academy was also present, and she subsequently made the necessary arrangements to enroll Mawaddah to a special school in Leicester.

In October 2015 Mawaddah was finally enrolled at Ash-Field Academy, one of the three special schools in Leicester. Due to her conditions, Mawaddah was classified as a pupil with Severe Learning Disabilities/Profound and Multiple Learning Disabilities (SLD/PMLD).

# OBSERVATIONS AND FINDINGS

#### Family Service Plan, and Education, Health and Care Plan (EHC Plan)

In a normal case, majority of pupils with special educational needs would be supported by their school, without the need of an EHC Plan. In Mawaddah's case, however, the needs were more severe, complex and persistent, thus an EHC Plan would be required to provide further support.

Around four months after Mawaddah was officially enrolled as a pupil at Ash-Field Academy, a Family Service Plan was drafted in an Early Support meeting chaired by the key worker in-charge of Mawaddah, and attended by the parents, health visitor, occupational therapist, speech and language therapist, visual impairment teacher, as well as class teacher. Reports from community GP, dietician, physiotherapist, psychology service, nursing and medical agencies were also used to draft the plan (Family Service Plan, 2016).

Overall, the plan contained reports on Mawaddah's current situation and abilities i.e. Mawaddah's general health update, her communication, eating and drinking, and learning and play abilities, explanations how she helped herself, how she got about, and about her home and family. The plan concluded with action plans to do for Mawaddah and the persons to whom the Family Service Plan report to be shared with.



Subsequently, based on the Family Service Plan, a more formal report called Education, Health and Care Plan (EHCP) was prepared by Special Education Needs and Disability Office, Leicester City Council. This EHC Plan was prepared in line with the statutory guidance set out in the Special Educational Needs and Disability Code of Practice (January 2015) and the Children and Families Act 2014 (EHC Plan for Mawaddah Mahyudin, 2016).

The EHC Plan contains important reports divided into several sections such as:

- 1. Mawaddah personal details
- Views, interests and aspirations of the child and the parents/carers
- 3. Special educational needs (Sensory/physical, communication and interaction, cognition and learning)
- 4. Health needs
- 5. Social care needs
- 6. Outcomes for Mawaddah
- 7. Monitoring arrangements
- 8. Special educational provision for Mawaddah (Teaching approaches and focused interventions, staffing arrangements, facilities and equipment, support from other agencies, SEND transport)
- 9. Health provision for Mawaddah
- 10. School placement for Mawaddah and other informational sections.

As Mawaddah parents, we observed that the EHC Plan clearly recognized her conditions as a pupil with SLD/PMLD hence the necessary support and requirements were outlined for her meaningful access to special education, such as:

"...teachers and classroom assistants who have knowledge and experience of working with a child with severe learning disabilities/profound and multiple learning disabilities (SLD/PMLD) and epilepsy" (EHC Plan for Mawaddah Mahyudin, 2016).

Furthermore, facilities and equipment required to support Mawaddah's learning process were also explicitly listed in the EHC Plan, such as alternative and augmented means of communication, specialist communication aids, as well as multi-sensory resources to promote her engagement, interaction, communication and concentration.

Annual review meetings would be done to report and evaluate Mawaddah's progress towards achieving the outcomes specified in the EHC Plan and any other matters relating to her progress, and to consider the continuing appropriateness of the Plan in the light of Mawaddah's progress. During our time, we had had two annual review meetings to discuss the above matters.

This was indeed a clear evidence of the advanced state of education system in the UK which would give equal access to special children especially those who were classified as SLD/PMLD like Mawaddah.

# Relevant parties involvement

As parents, we were involved in the decision making towards the provision of special education for Mawaddah since day one. We could attest to the strong commitment and involvement from all parties relevant to the education, health and care provision to Mawaddah. The parties involved, which we believed were quite comprehensive covering all her needs, were as the following:

- 1. Class teacher, assistant teacher and Principal
- 2. Community Pediatrician, Families, Young People and Children's Service, Leicester
- 3. Pediatric Cardiologist, Glenfield Hospital, Leicester
- 4. Ophthalmologist, Leicester Royal Infirmary
- 5. Dietician, Leicestershire Nutrition & Dietetics Service, Leicester
- 6. Educational psychologist, Leicester City Council
- 7. Family key-worker, Early Support, Leicester
- 8. General Practitioner, Victoria Park Health Center
- 9. Health visitor, Thurnby Lodge Children Center, Leicester
- 10. Occupational therapist, Families, Young
- 11. People and Children's Service, Leicester
- 12. Speech therapist, Families, Young People
- 13. and Children's Service, Leicester
- 14. Visual impairment teacher, Special Needs Teaching Service, Leicester.



#### About the school

Ash-Field Academy is one of the three schools in Leicester offering education to special needs children. Following the visit by the key-workers and the representative from Ash-Field Academy as earlier mentioned, we were then invited to visit all three schools and see for ourselves how the schools operate. We were also allowed to speak to teachers and the Principal and ask questions if we have any.

We decided to visit Ash-Field due to its closer location to our home, and upon visiting the school classes, seeing for ourselves the facilities and equipment, and discussing with the Principal, we decided to enroll Mawaddah to this school right away without visiting the other two. We were instantly impressed by the school environment that exuded confidence and positivity, and we were convinced by the extraordinary facilities and equipment and the reassuring and welcoming Principal and teachers.

The school housed 150 pupils from age 4 to 19 with diverse type of disabilities and of varying degrees. There were two two-storey buildings connected via a covered walkway, the first housed the classes, main offices, dining hall, and therapy rooms, while the second the assembly area and dormitories. In front of the school there were parking spaces.

We observed the facilities and equipment of the school were indeed state of the art, such as special wheelchairs of different sizes, standing frames, walking chairs, whereas the classrooms were equipped with superb IT instruments, special hoist, and there were various types of floor boards, and sensory toys and balls, as well all types of therapy rooms such as sensory, swimming, and light rooms.

The dormitories were meant for pupils with disabilities who were not severely dependent on carers or parents. They would be allowed to stay in the dormitories for a period of times to give their parents a short break, often called "respite."

The school was one of the highly reputable schools in the Midlands region. The school was the recipient of the "Excellent Spirit" award for three consecutive years in 2013, 2015 and 2017 from the Office for Standards in Education, Children's Services and Skills (OFSTED) UK in the agency's biannual assessments.

In the assessments, Ash-Field Academy scored "outstanding" for all OFSTED assessment criteria namely a) Achievement of pupils, b) Quality of teaching, c) Behavior and safety of pupils, and d) Leadership and management.

# About the classes

Number of pupils in Mawaddah's class was about 10. We observed that each class would have a teacher, and for each pupil there was one assistant teacher who would be assigned to support them in their daily class activities and interaction.

The assistant teachers would stay with the pupils throughout the day, and ensure they would participate in classroom activities such as singing, dancing, clapping, role playing, floor activities, and other movement activities, or playing with texturized toys and balls, or in activities during sensory therapy, hydrotherapy, occupational therapy and physiotherapy, or in activities outside classes such as playing roundabout and exploring nature.

Similar to Mawaddah, all her classmates were wheelchair-bound and non-ambulant. Their class was equipped with a special hoist installed to the ceiling to support the assistant teachers in moving the pupils into and out of the wheelchairs for class activities, especially the activities conducted on the floor.

The assistant teachers were also skilled in administering the prescribed medications to their pupils. We knew this because Mawaddah too was still under the epilepsy medication at that time and her daily intake would be administered by her assistant teacher.

During recess, pupils would go to dining hall, and Mawaddah and her classmates who were wheelchair- bound would be pushed by their assistant teachers to the hall. During this meal time, dining hall staff would attend to each pupil especially those who were severely dependent like Mawaddah to help them with the feeding.

However, we observed that the staff did not actually feed the pupils, but rather trained them with the skills to pick and hold the food with their fingers or spoon and fork, and to bring it to their mouths. We could clearly see Mawaddah's development in this type of skill which was quite interesting. Before coming to the UK, Mawaddah was still not able to hold food with her fingers, what more bringing it to her mouth.

Another interesting thing that we experienced here was that the parents were always welcomed to come to school whenever they wanted to for any reason. Indeed there were various school activities where parents were invited to join. We had experience of attending parent's coffee meetings, birthday parties (there



was once a pyjamas party!), Christmas celebrations, and school assemblies. Parents too were invited to join school visits to parks, animal farms or walk-around in the nearby areas.

The friendly atmosphere of the school, the amazing hospitality of the teachers, the concern and awareness of the Principal towards the development of each and every pupil under her care, had greatly impressed us.

We had had a very close relationship with the Principal, the teachers in Mawaddah class as well as other staff. Mawaddah seemed like to know and had somehow made good friends with almost everyone at the school.

## Home school diary

"This home school book has been designed to allow us to be in touch with you on a regular basis when required. Please note anything down that you think we may need to know." (Mawaddah's home school diary, 2015)

The above statement was written on the inside of the cover page of Mawaddah home school diary.

Each pupil would have a home school diary to record their daily activities at school. Via this book, the parents would be informed of their children's activities at school, or the new skills or achievements they had acquired at school. For pupils who were non-verbal like Mawaddah, the diary became an important mode of communication between teachers and parents.

To us, this was another interesting aspect of the special education in the UK. In the diary, there were plenty of new things we found about our daughter. Some of them were really surprising and many others would really make our day once we read them.

The following were among the postings jotted down in her diary by her teacher:

"Today Mawaddah helped celebrate one of our pupils' birthday. In the morning she spent time playing with toys and joining in with birthday games. Mawaddah experienced a massage story followed by intensive interaction – where Mawaddah had lots of fun making different shrieks, smirks and laughs, etc." (15/1/2016)

"Mawaddah was out of the chair enjoying the sensory room with her classmates. She seemed curious looking at different objects in our sweet shop role play. In the afternoon, Mawaddah relaxed during a cooking massage." (01/2/16)

"This morning she took part in a TacPac session as well as intensive interaction. This afternoon she

danced along to our action songs and also went for her swim – she did lots of splashing!" (3/2/2016)

"I got her working on the touch screen, making marks on a simple paint program. She was focused looking at the lines on the board." (14/3/2016)

"This morning Mawaddah had the opportunity to come out of her chair for a soundboard session based on different sounds of transport, followed by after break, a chance to explore our new underwater themed role play area. This afternoon, we felt, smelt, and tasted different foods we associated with the beach and holidays, including ice cream, ice and crisps."(8/6/2016)

"She has played with her friends on the roundabout and explored new herbs in the sensory garden." Mawaddah has also worked hard on her movement goal – moving items from one hand to the other." (1/9/2016)

"She loved dancing with her friends in movement and being outside in the Playpod. Mawaddah has also had her standing frame fitted and she stood for 45 minutes." (7/9/2016)



"She has really enjoyed intensive interaction and loved me playing a gentle pillow fight with her. She was giggling and smiling and making me repeat this." (9/9/16)

"Mawaddah has seemed slightly sleepy and sad this morning. We think she may have been slightly hungry as she was much happier after break. She has worked really hard in music today, she was letting people know when she wanted more by vocalizing!" (13/9/16)

"Mawaddah has once again worked brilliantly today. She found using the big macs during our sensory story hilarious!! Mawaddah also found dancing great fun and was really focused." (21/09/2016)

There were plenty more in the diary, and we believed these were a clear evidence of the milestones Mawaddah had achieved while attending special school in the UK.

Overall, we knew Mawaddah was an active pupil and had always wanted to take part in all activities in or outside class. Mawaddah was a joyful and happy child. She also loved music and liked rocking her head while listening to songs. Her teacher would always tell us that she rarely asleep during school except when she was too tired or had been under the weather.

There was another book to record how much food and drinks Mawaddah took during break. We were informed by teachers that this was important because sometimes Mawaddah might not eat much or refused to take certain type of food. This information would help us to know whether she was not feeling well, or to determine the suitable diet for her.

# School transport

School would begin at 9:30 am and end at 3.00 pm. All Ash-Field Academy pupils including Mawaddah would go to school by buses. Each bus had a specific school route to take based on the pupil's home locations, and each bus would transport around six to eight pupils depending on the bus size and whether the pupils use wheelchairs. For each bus, there was an assistant driver who would ensure the pupils were all safe and secured on their way to school.

Mawaddah's bus would normally arrive in front of our door around 8.30 am. The bus had only a few seats after some seats were removed to make space for Mawaddah's friends who were wheelchair-bound. They would board onto the bus via an automated ramp at the bus' rear door. On the floor where the seats were removed, there were security straps and hinges to secure the wheelchairs when the bus was on the move.

Mawaddah meanwhile used buggy to move around, therefore she would be put into a car-seat and secured with seatbelt. The buggy would be folded and put next to her seat. Mawaddah and her friends would arrive at school at around 9.00 am. In the afternoon the same bus would send Mawaddah and her friends home and normally Mawaddah would arrive home at 4.00 pm.

# EXHIBITS ON SAMPLE REPORTS, ACTIVITIES AND FACILITIES

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Figure 1. Family service plan

Name	Designation	Address	Telephone
Mother	Noor Asmin Khasaim & Mahyudin Ahmad	47 Diseworth Street, Leicester. LE2 ODB	0744 8788022
Consultant Community Paediatriciae	Dr Genesen	Families, Young People and Children's Services, Bridge Park Plaza, Bridge Park Road, Thurmaston, Leicester, LE4 8PQ	0116 2951350
Consultant Cardiologist		Glenfield Hospital, Groby Road, Leicester, LE3 90P	0116 2663082
Consultant Ophthelmologiet		Leicester Royal Infirmary, Leicester, LE1 SWW	0116 2586198
Dietician	Emma Jordan	Leicestershire Nutrition & Dietetics Service, Warren Park Way, Enderby, Leicester, LE19 4SA	0116 2727200
Educational Psychologist	Barbara Baker	Leicester City Council, Children and Young Paople's Service, Collegiste House, College Street, Leicester, LE2 0JX	0116-4545470
Family Keyworker	Sarbie Edwards	Early Support, c/o Menotys, 236 Narborough Road, Leicester, LES 2AN	0116 2823659
General Practitioner	Dr Linda Brown	Victoria Park Health Centre, 203 Victoria Park Road, Leicester, LE2 1XD	0116 2151105
Health Visitor for Children with Additional Needs	Louise Yarker	Thumby Lodge Children's Centre, Dudley Avenue, Leicaster, LE5 2EG	0116 2924890
Occupational Therapist	Kimberley Scott	Families, Young People and Children's Services, Bridge Park Plaze, Bridge Perk Roed, Thurmaston, Leicester, LE4 6PQ	0116 2952495
School Class Teacher	Rena Hutchins	Ash Field Academy, Broad Avenue, Leicester, LE5 4PY	0116 2737151
Speech & Language Therapist	Caroline Knight	Families, Young People and Children's Services, Bridge Park Plaze, Bridge Park Road, Thurntaston, Leicester, LE4 8PQ	0116 2955256
Teacher for Visual Impairment	Rachel Bland	Special Needs Teaching Service, New Parks House, Pindsr Road, Leicester, LE3 SRN	0116 4544650
Family Service Plan for: Managine	n Manyadas		Page Saf E
Date: 4" March 2016			1.600

Figure 2. The relevant parties involved

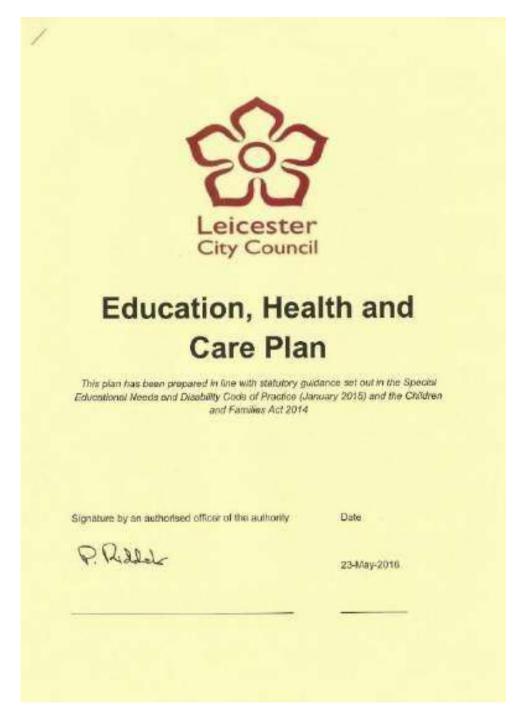


Figure 3. The front page of the EHC Plan



Figure 4. School wheelchairs and standing support



Figure 5. School bus



Figure 6. Meal session at dining hall



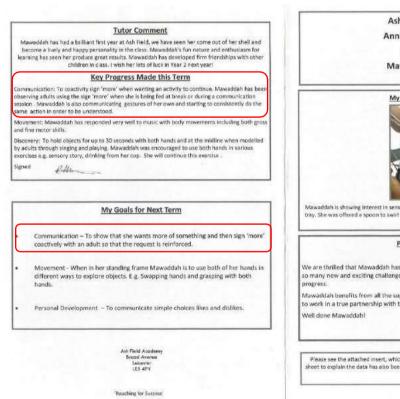


Figure 7. Sample of school activities





Figure 8. Therapy rooms and sample activities



Ash Field Academy **Annual Report to Parents** Summer 2016 Mawaddah Magyudin My Highlights of the Year Mawaddah is showing interest in sensory play and is being encouraged to investigate what is in the tray. She was offered a spoon to swirl the soggy cereal around, but Mawaddah preferred to use her hands. Principal's Comment We are thrilled that Mawaddah has joined us at Ash Field. She has responded very well to so many new and exciting challenges and it is wonderful to see her making such good progress. Mawaddah benefits from all the support from her loving family—thank you for all you do to work in a true partnership with the school. Please see the attached insert, which gives progress levels using PIVATS and attendance date. A sheet to explain the data has also been included and more information can be found on the website dle.gov.uk 'Reaching for Success'

Figure 9. Sample report to parents



#### CONCLUSION

Two years from August 2015 to July 2017 may not be long, but for Mawaddah, these two great years had brought out such a significant improvement in her skills and abilities especially in communication and movement.

For example, Mawaddah would interact with people around her by making certain sounds or pulling the person's hands when she wants to tell them something. Mawaddah seemed more alert to the surroundings, to sound, and to the presence of other persons. She seemed to have better social skills since she loved being cuddled and hugged even by strangers, and she also loved to be part of all activities taking place around her.

Mawaddah would roll on the floor to move her body towards the target, as she was not yet able to crawl. When she was on her back, she would hold both legs upright in the air and move around by rocking her legs and trunk. From lying on her back position, Mawaddah would press the floor or reach support around her to pull herself upright into sitting position. With support, she would be able to stand on her feet and this could last for about half an hour while playing or watching videos.

Mawaddah was a happy girl and loved listening to nursery rhyme videos on YouTube. She would rock her head from side to side when songs were being played. If we pause the video, she would vocalise, or sort of "scream" to us, as a way of telling us not to mess with her songs.

As far as her health was concerned, it seemed to be getting much improved. Two years in the UK, she was completely fits-free. This was so amazing since she had had quite frequent epilepsy episodes, almost every other months, during the year 2012-2015 until before we left for UK in August 2015. During our stay in the UK, she continued to attend hospital appointments at Paediatric clinic, Cardiology clinic for her ASD, as well as other clinics. Overall, she was fine during the two year period.

In summary, we had observed and experienced for ourselves the highly accessible and top quality special education in the United Kingdom. The integrated support system in our opinion would ensure successful delivery of the special education to the children. In addition, we bore witness the commitment of all parties to fulfill what were required of them to achieve this objective. To conclude, the policy and infrastructure for education and healthcare support for special children in the UK are state of the art, indicating a highly accessible and top quality special education in the country. Policymakers in Malaysia could learn so much from the UK in crafting the special education policies in line with the Malaysia Education Blueprint 2013-2025.

#### ACKNOWLEDGEMENT

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