**Berita Harian (20 May, p3), "Grandmother is only place for child with additional needs to depend on"**

Born premature at 34 weeks, Rayyan Sukri has never experienced the love of a mother or a father his entire life.

His mother was heavily involved with drugs and failed to show up at a urine drug screening. She was apprehended by officers from the Central Narcotics Bureau after delivering Rayyan at the hospital.

His father has also been jailed due to involvement in drugs. Both parents have been in and out of jail.

Mdm Sakinah, Rayyan's grandmother, had no other choice but to bring Rayyan home from the hospital following his birth. From that moment, Mdm Sakinah has been Rayyan's main caregiver. The child will be turning five years old this November.

When Rayyan turned two years old, Mdm Sakinah, 65, bought him a baby walker.

"(In my heart, I said) Why does the child not know how to move, he is often still", lamented the grandmother to 16 grandchildren, and mother of six children.

When she brought Rayyan to a health check-up, the family was informed that Rayyan had cerebral palsy and global developmental delay.

"My son (Rayyan's uncle) asked the doctor, who explained that this was a side effect of high drugs consumption. His brain was also affected," said Mdm Sakinah, who also said that Rayyan's mother continued to consume drugs while pregnant with him.

Till today, Rayyan had to frequent Singapore General Hospital and KK Women's and Children's Hospital monthly for eyes and ears screening, and to track his development.

All these is done by Mdm Sakinah herself, who travels via bus and train from her one-room rental flat in Toa Payoh. It gets a bit more difficult each day, as Rayyan continues to grow and put on weight, while Mdm Sakinah, who was petite in size, continues to age.

Thankfully, a special stroller was gifted to Rayyan from AWWA, a social service agency, allowing Mdm Sakinah to shuttle Rayyan from one place to another with greater ease. Rayyan attends early intervention sessions at the AWWA Early Intervention Centre (EIC) @ Kim Keat three times a week.

"I have to be strong. Sometimes, I have to thicken my skin and ask for help from other commuters to lift Rayyan's stroller up and down the bus," said Mdm Sakinah, who added that often times, bus drivers are unable to recognise that Rayyan's stroller was a stroller meant for a child with additional needs.

Taking care of Rayyan is no easy feat, and his needs are increasing as he grows older. The team at AWWA, made up of therapists, teachers and social workers sometimes visit Rayyan and Mdm Sakinah at home. They showed her ways of showering Rayyan, so that it was easier for her.

Head teacher at AWWA EIC @ Kim Keat, Ms Fazlinda Mohd Affendi Nasir, shared, "The first time Rayyan joined us, he did not have a lot of awareness, and was unable to do things that a typically developing child could do, such as sitting, standing or grasping objects. This was

why we equipped his grandmother with assistive technology such as the stroller, an activity chair and a bath chair for Rayyan."

Today, Rayyan has displayed improvements in his non-verbal response when someone is communicating with him. He has attained better head control and is able to maintain eye contact when others are interacting with him, added Ms Fazlinda.

Rayyan's social worker, Ms Nurharyati Mohammed Sa'at shared, "As a social worker, I often check in on Mdm Sakinah's well-being, as she often shares about difficulties faced in caring for Rayyan, and in shuttling him to and from hospitals. This way, there is someone for her to confide in, as she cares for Rayyan for 24 hours a day."

She also helped Mdm Sakinah, who is not working, attain additional assistance, in the form of diapers and milk formula.

When asked about her Hari Raya celebrations, Mdm Sakinah answered, "Hari Raya or not, it is it the same for me."

She said that there was not much preparations that she could do since she started taking care of Rayyan, as the demands of a child with additional needs was different. Her other children would send over Hari Raya dishes to her home, and visit her during the festivities.

"What else can I do? He is my grandson. It is not as if I will disown him when I heard that he has cerebral palsy. If he could speak, perhaps he would say that he does not want to be this way. I accept this gift of my grandson," said Mdm Sakinah.

"Sometimes, I do cry. I will tell Rayyan, - It's okay, Rayyan. I will be patient. You must pray that I am granted health and strength to take care of you. If I am no longer around, I do not know who else can take care of you," she added, her eyes glistening with tears.

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BERITA

# Hanya nenek tempat bergantung anak istimewa

## Ibu bapa dipenjara sejak kelahirannya dengan palsi serebrum, pembangunan lewat

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DILAHIRKAN pramatang pada 34 minggu, Rayyan Sukri tidak pernah merasa kasih sayang seorang ibu mahupun ayah sepanjang dia membesar.

Ibunya terjerat dalam kancah dadah dan tidak menghadiri ujian air kencing dan ditangkap pegawai Biro Narkotik Pusat (CNB) setelah melahirkan Rayyan di hospital.

Bapanya pula sudah di dalam penjara, juga kerana dadah. Mereka berkali-kali keluar masuk penjara.

Terpaksalah neneknya, Cik Sakinah Hassan, mengambil Rayyan dari hospital dan membawanya pulang. Sejak itu, beliau penjaga utama Rayyan, yang akan berusia lima tahun November ini.

Ketika Rayyan berusia dua tahun, Cik Sakinah, 65 tahun, membelikannya walker bayi.

"(Dalam hati saya) 'kenapa budak ini dah dua tahun tapi tak tahu bergerak, diam sahaja'," cerita nenek 16 cucu dan enam anak itu.

Apabila membawa Rayyan bagi pemeriksaan doktor, barulah mereka mendapat tahu dia mengalami palsi serebrum dan kelewatan pembangunan global (GDD).

"Anak saya (pak cik Rayyan) tanya doktor dan doktor kata ia adalah kesan sampingan dadah yang terlalu banyak. Otaknya pun rosak," ujar Cik Sakinah, sambil berkata ibu Rayyan terus menghisap dadah ketika hamil.

Hingga kini Rayyan perlu ke Hospital Besar Singapura (SGH) dan Hospital Wanita dan Kanak-kanak KK (KKH) setiap bulan bagi pemeriksaan doktor, mata, telinga dan pertumbuhannya.

Semuanya dilakukan Cik Sakinah seorang diri, turun naik bas dan MRT dari flat sewa satu biliknya di Toa Payoh. Semakin hari semakin sukar baginya. Rayyan yang membesar bertambah berat sedangkan Cik Sakinah, yang kecil dan kurus, kian meningkat usia.

Mujur ada kereta sorong khas yang diberi agensi perkhidmatan sosial AWWA, yang memudahkan neneknya itu membawa Rayyan ke mana-mana. Rayyan menghadiri Pusat Intervensi Awal (EIC) AWWA di Kim Keat tiga kali seminggu.

"Nekad sajalah. Kadang saya buat muka selamba dan minta tolong penumpang lain angkat kereta sorong keluar dan masuk bas," kata Cik Sakinah, yang menambah ada pemandu bas tidak sedar kereta sorong itu bagi kanak-kanak berkeperluan khas.

'TAKKAN SAYA NAK BUANG DIA': Cik Sakinah Hassan mengadu penat menjaga cucunya Rayyan Sukri sendirian kerana ibu bapa kanak-kanak itu di penjara sejak kelahirannya akibat kesalahan dadah. Namun, beliau terus menggagahkan dirinya kerana "dia cucu saya... takkan bila dengar dia ada palsi serebral saya nak buang dia". – Foto BH oleh SIN TAY

Menjaga Rayyan juga tidak mudah dan keperluannya berubah dengan meningkat usianya. Oleh itu, pasukan AWWA yang terdiri daripada pakar terapi, guru dan pekerja sosial mengunjungi Cik Sakinah, yang tinggal berdua dengan Rayyan, untuk mengajarnya cara memandikan kanak-kanak itu.

Ditemui di AWWA EIC @ Kim Keat, ketua guru yang menjaga Rayyan, Cik Fazlinda Mohd Affendi Nasir, berkata: "Bila kali pertama Rayyan menyertai kami, dia tak mempunyai kawalan yang banyak, dia pun tak dapat melakukan perkara yang dapat dilakukan kanak-kanak biasa, misalnya duduk, berdiri, menggenggam sesuatu.

"Itu sebabnya kami memberikan neneknya teknologi bantuan seperti kereta sorong, kerusi aktiviti dan juga kerusi mandi bagi Rayyan."

Kini, Rayyan menunjukkan kemajuan seperti memberi respon bukan verbal apabila orang bercakap kepadanya, mengawal kepalanya dengan lebih baik dan memandang ke arah orang berinteraksi dengannya, tambah Cik Fazlinda.

Pekerja sosial yang membantu Rayyan, Cik Nurharyati Mohamed Sa'at, pula berkata: "Sebagai pekerja sosial, saya juga selalu bertanya khabar Cik Sakinah kerana beliau sering mengadu tentang kepenatan menghantar Rayyan ke hospital dan menjaganya.

"Setidak-tidaknya beliau ada tempat mengadu kerana beliau saja menjaga Rayyan 24 jam."

Beliau turut membantu Cik Sakinah, yang tidak bekerja, mendapatkan bantuan tambahan dalam bentuk susu dan lampin bagi cucunya.

Ditanya tentang sambutan Aidilfitrinya, Cik Sakinah menjawab: "Hari Raya tak Hari Raya, sama saja".

Sejak menjaga cucunya itu, tidak banyak dilakukannya kerana "jaga anak istimewa, penatnya lain", kata beliau. Anak-anaknya yang lain menghantar juadah Hari Raya dan menziarahinya setiap tahun.

"Apa nak buat, dia cucu saya. Takkan bila dengar dia ada palsi serebral saya nak buang dia kan? Agaknya kalau dia boleh bercakap, dia cakap, 'nenek, Rayyan tak nak jadi macam gini'. Kita terima sajalah, dia kan anugerah," ujar Cik Sakinah.

"Kadang, saya nangis juga. Saya cakap dengan Rayyan, 'tak apalah Rayyan, nenek sabar, Rayyan doakan supaya nenek sihat dan kuat jaga Rayyan.

"Kalau nenek dah tutup mata tak tahu siapa lagi yang nak jaga Rayyan'," tambah beliau, bergenang air mata.