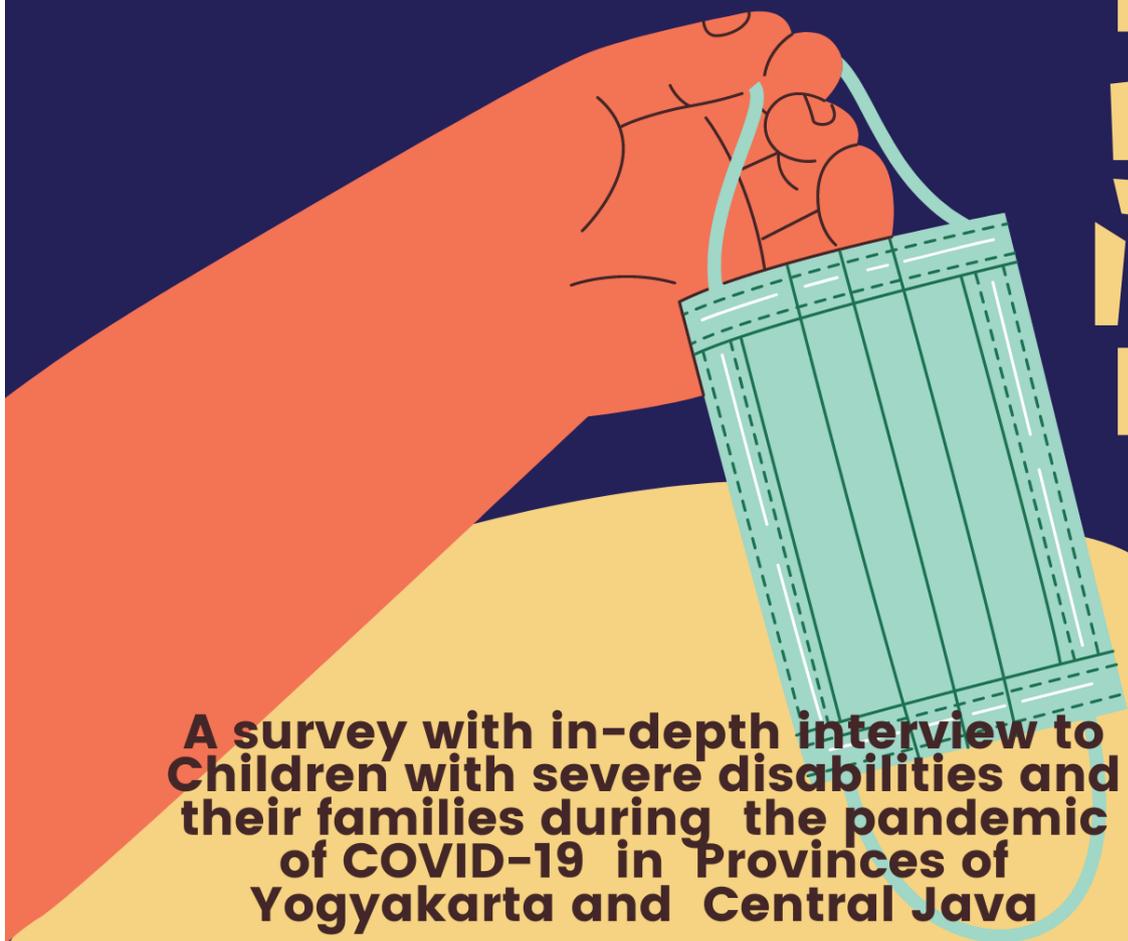




STAY STRONG, MY CHILD...



A survey with in-depth interview to Children with severe disabilities and their families during the pandemic of COVID-19 in Provinces of Yogyakarta and Central Java

Executive summary

Covid-19 pandemic has not impacted to health issue only, but also economical crisis from macro institution (state) to micro institution (family). More areas both states and villages have been conducting limitations of human's migration, therefore it has been causing economical routes obstructed. The states have been facing a dilemma between protection for people's health issues and economical support for people.

This situation makes people have been depend on government supports. Although common people needs those support, however marginalized and vulnerable people groups are more affected especially persons with disabilities. They has specific needs but careless into government policies during the pandemic. The persons with disabilities need policies and handling inclusively based on their disability needs.

The OHANA INDONESIA and DISABILITY RIGHTS FUND conducted a survey equipped with an in-depth interview to twelve families having a child/children with severe disability (s), two teachers with disability and a therapist on Province of Yogyakarta covering five districts and one municipality. Not only in that province but also in District of Magelang in central Java. This resume would study related two issues namely impacted economic issues and government's programs for persons with severe disabilities and their families.

First of all, related to impacted economic issue. The survey was conducted to twelve families who having children with disabilities, two teachers and one fisiotherapist. Most of them (before the pandemic) already received the government's support to poverty alleviation programs. It means that they were in poor condition. Government's support such as Bantuan pangan non tunai (food support-cashless), welfare family program, Healthy Indonesian card, for examples, the survey showed that there were six families receiving those programs. But there were two families could not accessed them because of civil identity matters.

Because of the pandemic, all surveyed families agreed that they should received support programs to help their family economically and health matters. Average parents' background were informal workers and entrepreneurs.

Second, related to government's support programs. During the pandemic, Indonesian government had issued programs to increase people's welfare. Based on data of National development planning institution (BAPENAS) at least there were 7 programs during the pandemic given for people regularly (each months) and non-regularly (once in that program), such as:

- 1. Pre-work card - kartu pra-kerja (April-Oktober/nopember 2020)*
- 2. Basic food program - Program sembako (April-desember 2020)*
- 3. Welfare family program - Program Keluarga Harapan (April – Desember 2020)*
- 4. Basic food from President's support - Banpres Sembako (only in jabodetabek area)*
- 5. Social support cash - Bantuan Sosial Tunai (April -Desember 2020)*
- 6. Electricity support - Bantuan Listrik (April-September 2020)*
- 7. Village support cash - Bantuan Langsung Tunai Desa (April-September 2020)*

Although several surveyed families stated receiving government's support such welfare program and basic food program, but those were received by them because of the pandemic reason. They should received other programs related to the pandemic.

Related to health care insurance (including therapy care), They stated that they were covered by BPJS program (government's health insurance), however there were two families stated that they were not covered by the BPJS because of a civil identity matter. They did not have identity card in accordance with area their living. A family objected with rules of the health insurance regulation related to physiotherapy care fee just for child age (below 18 years old).

Another program related to pandemic of covid-19 concerned to prevention efforts, all surveyed families stated that they never received it. They never received information properly related to covid-19 and prevention protocols. During physical distancing policy implemented, most of parent and their children were impacted. They had to visit therapist or hospital, but they could not. Moreover, persons with disabilities having comorbidities making them more vulnerable. (BYG)

Singkatan / *Abbreviation*

AVO	<i>Ankle Foot Orthosis</i>
APD	<i>Alat Pelindung Diri</i>
	<i>Personal protective equipment (PPE)</i>
BPJS	Badan Penyelenggara Jaminan Sosial
	Social Security Administrator for Health
BNPT	Bantuan Pangan Non Tunai
CP	cerebral palsy
IFI	Ikatan Fisioterapi Indonesia
	Indonesia Physiotherapy Association
KIS	kartu Indonesia sehat
KK	Kartu Keluarga
LKS	Lembaga Kesejahteraan Sosial
NIK	Nomer Induk Kependudukan
OHANA	Organisasi Harapan Nusantara
OT	occupational therapy
PKACP	paguyuban keluarga anak Cerebral Palsy
PKDAC	Paguyuban Keluarga dan Anak <i>Cerebral Palsy</i>
PKH	Program Keluarga Harapan
POTADS	Persatuan Orang Tua Anak dengan Down Syndrome
SI	Sensori Integrasi
SLB	Sekolah Luar biasa
UCP	Unit Cerebral Palsy
WKCP	Wahana Keluarga <i>Cerebral Palsy</i>
YAKKUM	Yayasan Kristen untuk Kesehatan Umum

Felisa: a child with hydrocephalus can not receive therapist-care.

“The COVID-19 pandemic caused Henny and her family’s economical condition to worsen. Her husband could not work for 4 months. They can only rely on government allowance or social organization support. Now Henny’s husband had returned to work, although only for half a day and reduced salary. This loss of income caused Henny and her family to rack their brains to afford their daily needs.”

Felisa Dewi Kirana does not seem to be different from her peers. Her smile and shy laugh hides the fact that she needs a walker to help her walk.

The girl called Felisa is now in primary school. She has multiple medical conditions, cerebral palsy, hydrocephalus, and Global Developmental Delay, thus the special treatment that she receives at school.

“At the beginning of first grade, Felisa’s friends needed some time for adaptation. But when her friends started to care about her, eh, Corona.” Said Felisa’s mother, Henny Setyani, when interviewed on Tuesday, 1 September 2020 in Depok, Sleman.

Felisa is a good kid who is kind towards her friends. She makes friends easily and loves school. She was so excited and happy to meet new friends when school started. However, she had seizures that night due to exhaustion. She has to up her medicine dosage. This became an important lesson for Felisa.

Henny revealed that Felisa’s current condition is better compared to when she was an infant. When she was 4 months-old, her attending doctor suspected that Felisa has hydrocephalus. Henny was shocked and she went to have Felisa checked up straightaway. CT scan result shows that Felisa does have hydrocephalus and needed to have tubes inserted immediately.

“At that time, no matter what operation was done to her, her life expectancy would not reach 2%. We were highly stressed. “

The expense of medication and the low chance of the operation being a success scared Henny and her husband. Her family was not insured with BPJS at the time. Henny is a housewife, while her husband is a caretaker of someone’s homestay.

Henny decided to proceed with Felisa’s operation when she was 7 months-old. She received help from college students who raised funds for Felisa’s operation through social media. Henny’s friend also helped so that Felisa could be operated and afford the millions needed to pay for the tubes.

Henny’s worries started when Felisa was about to be operated. Felisa faced many problems, such as allergies to the anesthesia. Henny was terrified when three children in Felisa’s room passed away. However, her worries went away when Felisa survived her operation.

Eversince the operation, Felisa routinely takes medicine and goes to therapy. The cost for her treatment is covered by BPJS. Henny prioritized to take care of government aid such as BPJS. Felisa’s

condition keeps improving. She can walk for a few steps without her walker, though she needs to hold on to something every once in a while, so she would not fall.

Keeping achievements like others.

Medicine and therapy helped Felisa to get better. She even has some achievements, such as winning in a colouring contest. Besides, Felisa also started to do some modelling.

“Of course, there are kids that make fun of her, (why is she) grown but could not walk. She got dressed up during Kartini Day and someone said “Why are you wearing a Kartini dress? You can’t walk” (comments) like that exists” revealed Henny

But none of them extinguished Henny’s spirit. She keeps on supporting Felisa in creating and socializing. She wishes that Felisa can be independent. She also wishes that Elisa can have a chance to learn without being discriminated against for her disability.

“Do not judge children, do not compare them to one another. Abled children varies in their talents, so do disabled children. That is not a choice for her, she did not choose to be disabled. Although she could not walk, it does not mean that she can’t have a normal childhood” Henny continued.

Henny also received a not-so-pleasant experience when her neighbours were talking about her. The neighbours were discussing about how Henny is not involved with neighborhood community because she has to take care of her daughter. Henny could not leave her daughter alone either. She even has to stop working after having Felisa because she has to take care of her.

her health decreasing

There are times when Henny became worried about Felisa because she is more vulnerable to diseases than other kids. Especially during the COVID-19 pandemic, Henny tries to take extra care of Felisa. The pandemic also caused Felisa’s condition to worsen.

Felisa has to routinely take medicine and therapy in the hospital. Without the treatment, Felisa could fall and injure her head. She could also get seizures. Henny could pick up the medicine without Felisa. However, therapeutic treatment are being limited and caused Felisa to miss her routine therapy. “Felisa does SI (Sensori Integrasi), OT (occupational therapy), as well as physiotherapy. Physiotherapy during the time when she could not walk properly.)

Henny could not administer the therapy herself because she does not know how and she would not risk harming Felisa. This condition worsens due to the therapeutic treatment in hospital (where Felisa receives physical therapy) is not covered by BPJS.

“BPJS has an age limit (when children can only be covered by BPJS for therapy) until 7 or 8 years old. I don’t know whether or not Felisa can still continue her therapy in the future with BPJS’ age limit for children with disability. “ said Henny.

The condition worries Henny because Felisa still needs therapy. Whether she wants it or not, Henny has to pay for her daughter's therapy when her BPJS card expires. On the other hand, her family is having economical hardship.

The pandemic making matters worse

The COVID-19 pandemi worsens Henny and her family's economical condition. Her husband had to stop working for 4 months. They were reliant on governmental or NGO aid. Now that Henny's husband had returned to work, although only for half a day and with reduced wages. Henny and her family had to find an idea on how to fulfill their daily needs.

There is no governmental aid for the therapy costs, even for personal protective equipment for COVID-19. No supplemental help, although children such as Felisa are the most vulnerable against the disease.

Henny wishes that the government would pay more attention to children such as Felisa. She wishes there would be more information available for parents with disabled children.

"If there would be representatives in the village that could help to figure out whether a child is disabled or not. Maybe through screenings for children when they are going to the integrated service post. Whether the child is disabled or not." She finishes. (Ayun 1)

Less Facilities for Children with Cerebral Palsy Friendly

“The COVID-19 Pandemi also impacted to Siti’s family’s economical condition. Siti is a housewife, while her husband is a (*coolie? Might be considered as a slur*). They could only rely on the income from selling sand and governmental help in the form of Bantuan Pangan non-Tunai and Program Keluarga Harapan. They do not receive special support in terms of the countermeasures against COVID-19 such as Personal Protective Equipment od supplements. “

Ahmad Imam Mujtaba (16 years old) could only watch other children run and play in front of his house. He sat on his wheelchair given to him by Organisasi Harapan Nusantara (OHANA) He could only observe his friends riding their bicycles or playing hide-and-seek. Maybe in his heart he wishes to be able to run like them. Written on his face how he is happy and enthusiastic. He could not bear to stay at home all the time. Due to his cerebral palsy, he could not walk like other children.

Imam, as they call him. Like his namesake, his family wished him to become a good leader one day. Imam was known to for his love of storytelling. Although he was shy to tell a story to someone that he had just met.

Imam loves to solve puzzles and listen to dangdut music. He also loves to sing. He wants to be a singer like Didi Kempot. His parents tried to facilitate Imam’s hobbies and talent by buying him a microphone and a speaker.

Imam is a happy kid, despite the limitations that he has. Once he got jealous of his younger sibling because they were able to walk. He also often feels bored for staying at home for a long time. His disability caused him to have to be able to get whatever he wants.

“If he does not get what he wants, he would cry and throw a tantrum. He would also slam his speaker”, said Siti Hidayati, Imam’s mother when interviewed on Friday August 28 2020 in Salam, Magelang.

Imam’s birth was Siti’s great hope as he is her first child. Imam was born normal, about 4 kilograms. The midwife gave Imam his vaccination. While the midwife was not done injecting the vaccination into Imam, his body turned blue and he became unconscious.

Imam was rushed to the regional public hospital. The doctor inserted oxygen tube and put Imam into an incubator. Imam fell into a coma. After 10 days, Imam regained consciousness. The doctor asked Siti to breastfeed Imam for 5 days, and he was allowed home. Imam’s weight decreased 1 kilograms. Siti asked the doctor whether anything was wrong with Imam, but the doctor said that everything was fine.

When Imam was a few months old, Imam has to be checked out to the health centre due to spots in his lungs. Siti revealed the mishaps that cause Imam to go into a coma. The doctor in the health centre speculated that there might be a mistake in the delivery of the vaccine that caused Imam’s slow development. The doctor also revealed that Imam has cerebral palsy and hydrocephalus.

“I had many difficulties (to afford Imam’s healthcare), because we did not have BPJS at the time. So when we (get Imam) checked out, we have to pay like regular patients, although we only have meagre income” Siti clarified when she recalled that time.

Siti’s worries kept on growing. Sometimes she wonders why her child could not walk like other children. When Imam was younger, he used to ask “Why can’t I walk, mom?” Siti tried to cheer Imam by answering that “You’ll be able to walk when you are grown”

Siti tried many ways to help Imam’s recovery, especially through physiotherapy. Before fdoing therapeutic treatment in the hospital, Imam’s condition was pitiable. His feet kept on shrinking, his weight depleting. After routine physical therapy, Imam gained weight and his legs went back to their previous size.

Coping with The Pandemic

As a mother, Siti always worries about Imam. Imam often gets seizures when he was younger, due to lack of oxygen to his brain. When Siti was home alone with Imam, Siti would massage him and pats Imam’s body to help him to get conscious, but to no avail. Siti also gave Imam water to drink due to her lack of knowledge that we should not give people water while they are seizing, that we have to wait until they are done. Siti could only wait until Imam came to.

Siti now has more knowledge from the informations that the doctor gave her regarding taking care of children with cerebral palsy. Imam now routinely takes medicine and does long-term therapy. Lateness in taking his medicine would cause Imam to have seizures.

“Besides, there is also the physiotherapy every week. If Imam was not well, his seizures would last longer. Corona caused his therapy to stop. He fatigues easily because of that. His body is stiff, unlike the relaxed state that he usually is when he can go to the physiotherapy. “ explained Siti.

Siti can still pick up medicines in the hospital. But the hospital only gave self-physiotheraoy lessons online. Imam often moves around a lot when his parents attempted to give him the therapy. It was different than in the hospital, when Imam was obedient to the doctor.

The pandemic also affected the family’s economical condition. Siti is a housewife, while her husband is a (coolie can be considered a slur?). The pandemic caused her husband to stop working. Siti tried to make food and sell it through shops as an alternative income.

They could only rely on the income from selling food and governmental support such as Bantuan Pangan Non Tunai (BPNT) dan Program Keluarga Harapan (PKH). They do not receive special aid regarding COVID-19 such as PPE or supplement. Although children with cerebral palsy like Imam has a vulnerable immune system, making them more vulnerable to viruses and diseases

Less facilities for PWD friendly

Siti often feels jealousy to other children. She wants to send Imam to school like other children, though Imam’s difficulty in handling writing utensils caused him to not be able to handle school. Beside, there are no inclusive schools in the neighborhood. There is only schools for special needs children, though Siti would not send him there due to her fear of Imam being sad and affected by his friends’ experience, since a friend of Siti had an experience like that when sending their child to special needs school.

Imam could only stay at home due to the pandemic and the road around their house are not suitable for wheelchair. The road from Imam's house to the village road over 50 metres away are not paved not asphalt, only a path. Imam could not explore the environment around him.

"Imam could only use his wheelchair inside. It is difficult to use it outside because it is slippery. Usually other children have to push his wheelchair because it is heavy." Revealed Siti.

The Friday call to prayer reminded Siti when she used to carry her son to the mosque. She used to be strong enough to carry Imam and took her to the mosque for maghrib and isha prayers. Imam was also excited for Friday prayers.

"Imam is always so excited when I took him to the mosque." Said Siti.

They never did that anymore. Lack of accessibility for wheelchair on the road to the mosque is the main reason why. Besides, the mosque does not provide facilities for disabled people. The only way that Siti could think of was to leave Imam outside when he wants to join the Friday prayer, but Siti could not bring herself to do that, besides, she is worried if Imam feels scared when he is outside the mosque alone.

Siti does not only face this difficulty outside. Their home also lacks adequate facility to help ease Imam's activities. When Imam had to go to the bathroom, Siti has some difficulties to lift Imam to the toilet. So was the problem when Imam needs to take a bath. This made Siti realize that Imam is also burdened by his condition.

"I wish Imam can be like other children, being able to walk and write. To see Imam's development, I believe that Imam will get better. Imam could not talk before, but now he could," said Siti.

Siti also wishes that the government would pay more attention to children with disability like Imam. They need disability-friendly facilities in public and in private so they can do their activities like every other kid. (ayun2)

The Pandemic Hinders Children with Down Syndrome's potency

"The government said to use a mask, eat nutritious food, dear god, we can barely afford to eat, let alone nutritious food." Said Kiki

People stared at Mirza Rahman (23) on a rickshaw going to his house. Mirza was a child then, he just got back after a few years living in Australia with his mother. These stares made Mirza uncomfortable. His mother, Sri Rejeki Ekasasi realized that these people do not understand about down syndrome that her child has. Mirza, used to speaking English, asked his mother "Why (are?) people staring at me?"

The mother, usually called Kiki, smiled and answered, *"Because you are awesome, because you are nice, you are cool, you are handsome!"* Mirza smiled and felt confident because of his mother's words. He relaxed on his seat, said hi to the left and right, even waved at the passerby while saying *"Mommy, people staring at me because me awesome. They like me!"*

Full of emotion, Kiki recalled that memory when interviewed on Sunday, August 30 2020 in her house in Kapanewon Kraton, Yogyakarta. Mirza who was there wore a proud expression on his face.

Mirza was one of thousands of stigmatized children due to having down syndrome. People even call him "cah edan" which meant crazy kid. Kiki told us that the incident broke Mirza's heart and she was quick to console Mirza.

"Ofcourse, there are feelings of discomfort when people talk about (Mirza) and stigmatized "he has down syndrome, he is like this, he is like that" So we tried to taught our kids to be strong when people call them mean names," said Kiki.

Kiki felt lucky since she does not face the same challenges as other parents with children with down syndrome. Kiki's husband did not accuse her of infidelity when she gave birth to Mirza. There is a stigma that children with down syndrome is a result of infidelity or some sort. Besides, Mirza has the support and love of his family so he can grow optimally. Many children with down syndrome are neglected or even disowned by their family.

Realizing this social phenomenon, Kiki joined Persatuan Orang Tua Anak dengan Down Syndrome (POTADS) in 2010. In 2013 up till now, she is the head of the organization.

Many parents were unsure of their children's future with down syndrome. They would not join the POTADS due to fear from being stigmatized by the community. As time passes, Mirza's presence motivated and inspired them. They were amazed because Mirza's independence, his fluency in speaking English, passion in photography, until swimming. This encouraged them to understand and accept their children and becoming more active in POTADS.

Mirza and his art works

Kiki's presence in POTADS does not only bring hope to other parents, but also developed Miza further. Mirza's daily activities has a good range of variety, such as biking, painting, crafting, to hip-hop dancing.

Mirza loves biking. He usually bikes around the house with Kiki. Besides, he also has many works of art. He would display a box-full of his paintings on canvas proudly. He would also display some colouring books. He would tell each stories behind his artworks enthusiastically. His paintings once was displayed in a showcase, he even sold some of his paintings.

Mirza is also currently invested in hip hop dance. Besides training, Mirza also creates his own choreography. He performed in many events, even in once in national tv. He trained this skill when he was in high school extracurricular. He is also self-taught from Youtube. Mirza is a member of a dnce group named Nalitari, where there are other children with special needs. Mirza really enjoys their rehearsal time.

Mirza's dreams

Mirza and his friends' activities in POTADS are very productive. From fashion show rehearsals, music rehearsals, and other activities to develop their soft skills. They produced many crafts and paintings, they can even earn money from their crafts.

With that realization, Kiki developed a plan to open a shophouse dedicated to children with special needs, such as down syndrome. This plan goes hand-in-hand with Mirza's aspirations.

"I wanna be Superman. Selling paintings, craft kits, colouring books with my own brand, Mirza Brave. I'll sell" revealed Mirza when we asked about what he wants to do in the future

Mirza is rather self-reliant in his steps in reaching his goals. Mirza loves to learn from YouTube, especially watching DIY video tutorials. He would follow along with the video to create his craft.

POTADS members also has similar agenda, Not just creating crafts, but other artforms such as dancing. These dances are performed in many events..

Unfortunately, the COVID-19 pandemic halted almost all activities. Members' productivity is also reclining. Mirza asked why children are no longer attending rehearsals, Kiki answered, "due to Corona." Mirza could not bike outside his house anymore either.

No supports

Mirza and his friends in POTADS never received any help for children with down syndrome. Even basic aids such as personal protective equipment is not given out to them.

"The government said to wear a mask, to wash our hands, to eat nutritious food. Dear god, we can barely eat, let alone affording nutritious food. " revealed Kiki.

Kiki also revealed that there are parents in the POTADS that had gotten fired recently. Thus, their difficulties with basic needs and affording personal protective equipment. The needs for therapy for the children is also more difficult to be fulfilled due to the pandemic and the economical condition. They are forced to buy their own personal protective equipment so they can continue their works.

Children with down syndrome are highly dependent on their parents as long as they are not able to support themselves. Sometimes neighbour and family relatives can babysit? for them, but only if the relatives or neighbours are willing to take them in, since some children are tantrum-prone. So their parents have to take them to work.

“When we take them to work, we all have to obey the health protocols. They have to have hand sanitizer, a mask, and even face shield. But it is difficult for us to afford those.” Continued Kiki.

Kiki wishes that the government would give a good example facility, direction, legal aid, and others for children with down syndrome. These policies will be put in place in hopes that children with down syndrome can be self-reliable and can have a role in the community.(ayun3)

Fifteen Years Saripah's struggle to Liberate Her Daughter

"Fatiah's main needs that has the most impact (on the family's economical condition) are therapy and diapers. Luckily we do not go to therapy often as we can self-administer therapy at home, so at least it cuts off the therapy costs. However, we still need to buy diapers so she can go to the bathroom,"

The sun blazed on Asrama Muadz bin Jabal in Wirobrajan, Yogyakarta. A middle-aged woman was sweeping her yard. Helped by her broomstick, she cleaned the trash. Afterwards she came back inside to take care of her children.

The woman was none other than Saripah (43), a stay-at-home mother of four. Her husband, Samsi (43) worked as a teacher in a private school in Mualimin, so Sari, her nickname, took care of her four young children. She held up the burden when her oldest child was diagnosed with severe cerebral palsy.

Sitting in her guest room, Sari told the story about her child with cerebral palsy. In April 25 of 2005 in Brebes, she gave birth to her oldest child, named Fatiah Nur Rohmah. Curious incidents started to happen the day her child was born. "A day after I gave birth, my child had seizures so they had to be put in ICU for intensive treatment." said her.

Two weeks passed, Faatiah has not shown any good development. Fatiah's seizures caused Sari and her husband to move to Yogyakarta so their child could receive better treatment in Dr. Sradjito hospital. From what the doctor said, this condition was caused by lack of oxygen supply, hypoxia, due to the long process of birth.

The doctor first suspected that Fatiah's condition was caused by a heart condition. This suspicion was supported by Fatiah's blue face and small head circumference. Sari decided to take Fatiah to therapy routinely, twice a week, routine medicine consumption, and routine check ups in hopes that Fatiah would get better soon.

But fates unwilling, Fatiah has not shown any significant improvement, and Fatiah's seizures continues. Sari started a research to find out a doctor with extensive experience in childcare. She came to Prof. dr. Sunartini, P.hD, SP.A(K), a child specialist in Sardjito hospital in Kotagede, Yogyakarta, after her relative told Sari about her

After a consultation with Prof. Nartini, Fatiah has a new diagnosis. Cerebral palsy, caused by hypoksia. "medicine would not make much difference. The sstroke-like seizures was caused by a problem in Fatiah's brain that affected the oxygen supply to the brain. Operation would not help much either," clarified Sari, repeating what Prof. Nartini said at that time.

Fatiah spent half her life on her bed ecause of her condition. This could also damage her lungs due to spending an extended period in bed may cause a virgo-like condition in adults, but worse for Fatiah.

When Fatiah turned two, Sari and her husband decided to let the doctors operate on Fatiah's brain since the medicines does not work. "Our hope was to reduce the frequency of her seizures, we felt horrible looking at Fatiah and her condition. Besides, there is also her dependency to the drugs," said Sari while holding back her tears.

Luckily, Fatiah gradually got better after her operation. Sari remembered that Fatiah does not have seizures as often, and she started to show some response when communicated with.

The most touching moment that Sari remembers is when she and her husband felt exhausted waiting in a queue for Fatiah's routine check-up post-operation. Fatiah suddenly laughed, and that made Sari happy. Fatiah motor skills also improved, as she held on tighter than she usually does.

Sari also remembers the hardships that she went through with her husband. "It was 2008, social media and technology was not in the state that they are today, so our husband and I had to do our research on our own. Often we came into hurdles when trying to find information about treatments for Fatiah. So we had to find informations everywhere," she complained.

Another thing that burdened her was the fact that Sari and her husband had to pay for all of Fatiah's medical cost on their own because they did not have insurance yet. Thus, they spent a lot of money. Besides, they also had to keep Fatiah's three siblings clothed and fed. Sari revealed that she never received any aid from the government for 15 years, despite Fatiah being registered in the family's civil records

The presence of insurances such as BPJS in 2013 does not relieve Sari. The bureaucracy involved makes it difficult for Sari and Fatiah to be mobile. Besides, the lack of accessibility in public for physical and non-physical treatments were not as improved as now. These were the main causes of Sari not continuing to apply for insurance.

Fatihah has two wheelchairs. One was given to her by Ohana association that was custom-made for her, so it can be set in an inclined angle. According to Sari, this wheelchair helps greatly with supporting Fatiah's mobility due to its ergonomical design. However, they could not carry this wheelchair everywhere because of its size and that they could not fold it. The other is a regular wheelchair. "So when she goes out the house, she uses the regular wheelchair, cushioned on the sides with pillows so it would not hurt as much," she explained.

Sari still feel grateful of her chance to receive free therapy for Fatiah from Yakkum Rehabilitation Centre in 2013, along with education regarding simple therapy for children with cerebral palsy, that now helped her to self-administer therapy during the pandemic. Sari's educational background as a pharmacist also assists Sari in the therapy. Although there are times when she feels exhausted from taking care of all Fatiah's sibling, when she would call a specialized physical therapist.

As time went on, Sari felt that the routine therapy in Dr. Sardjito hospital does not provide information access regarding cerebral palsy. She decided to continue the therapy in the place of the late Ms. Nawangsasi in Surakarta in 2012. Twice a week Sari took Fatiah to Surakarta with her siblings in a train. It became a special challenge for her. Sari received many knowledge and insights about children with cerebral palsy from the late Ms. Nawang.

Fatihah's condition worsens when she turned 10 due to spastic (the narrowing of muscle in children with cerebral palsy) that caused dislocated spine. Fatiah now could not sit properly as before,. Before her spine dislocated, Fatiah can stand up straight for two hours, but now she can only do so for a few minutes. Her hand also balled up tightly.

Long story short, Sari took Fatiah to Dr. Sardjito hospital for intensive treatments and laboratory tests. Sari pushed the doctors to operate on Fatiah because she could not bear to see Fatiah crying in pain. This operation can also reduce Fatiah's risk of getting scoliosis and damages to her muscle.

Fate wills otherwise, the doctors refused to operate on Faatihah because it would barely change anything for her. Sari could not help but to cry. Sari started to find an alternative healing methods. "I can only hope that Fatiah can get better soon, whether through therapy or alternative methods," she sighed.

Now fatiah spends her days laying on her bed, not much different from before the pandemic, but now Sari often sits outside with Fatiah in the sun for some extra vitamin D production.

Sari continued about the effect of the pandemic that caused reduced hours in her husband's job. The reduced teaching hours also means reduced wages, despite the rising cost of daily lives. With Fatiah's extra needs, Sari and her husband had to find ways to manage their budget.

"Fatiah needs that we feel cost the most is therapy and diapers. Now that we can self-administer therapy at home, so it cuts the cost. But we still need to buy diapers so Fatiah can go to the bathroom," she explained.

It is a pity that Fatiah has not been able to access formal education at the age of 15. According to Sari, she tried to enroll Fatiah in one of the favourite special needs school in Yogyakarta, but Fatiah was rejected due to her inability to communicate in two-ways. She also tried to enroll Fatiah in other special needs school, but they resulted in more rejections. Sari decided to not send Fatiah to school up until now due to this experience, she closed her story.

Sari tried to build an inclusive and educative environment around Fatiah, teaching Fatiah's siblings about her condition. Aisyah, (7) usually helps pushing the wheelchair, Nadiya (6) helps to feed Fatiah, and Kamila helped to prepare Fatiah for baths.

"I am thankful that my three other children are very helpful and understanding of their sister. Once they were fighting because they all wanted to help push their sister's wheelchair. I was touched when I see that. I wish that me and my husband live long enough to take care of Fatiah. If one of us does pass away first, we wish that our children will be ready to take care of Fatiah." She concluded. (*bima1*)

A Mother's Story Hunts A Therapy Care while The Pandemic

“When I see Maman getting tired, I bring him to the masseuse as the last alternative. Although it is not as efficient as physical therapy, but I had no other choice. At least the massage would reduce his convulsions so it would lower the risk of his brain and motor ability. I can only hope that the pandemic would be over soon so Maman can go back to his physical therapy like before. “

A widow with two children who lives in a simple joglo house in Gunungpring Muntilan. The passing of her husband two years ago made Khoiriyah (41) the main earner of the house.

Khoiriyah is a mother of two who works by selling cakes and renting tents. She has to work by herself due to the passing of her husband and her first child dropped out of school and has some mental issues. She admitted that her responsibilities became harder to fulfil ever since the pandemic started five months ago.

Meanwhile, a little boy seemed to be dragging his feet from one of the corner of the house, trying to come closer to Khoiriyah. Khoiriyah's second child, Kholilurrohman (10). Kholilurrohman has a severe cerebral palsy. Maman, his nickname, usually used a wheelchair given by Ohana Foundation that was designed to fit his needs to support his mobility at school or at home.

Maman used to go to SDN Gunungpring 3 Muntilan and reading the quran, now has to stop doing those activities due to the COVID-19 pandemic. Maman told us about his routine before the pandemic. He goes to school from 7 am to 1 pm. And then he goes to the TPA until 4 p.m, and then he would continue with reading the quran until 4 the evening call to prayer. “After reciting the quran, I would go home to do the ablution, and then back to the mosque for the Isha prayers. And then I would go back home to rest,” he stuttered.

Now Maman spends his time at home with his monotonic activities. Online school, reciting the qura, and watching kobro performances on TV. The monotony bores him.

Maman admitted to miss going to school, especially when his teachers paid attention to him, or when his friends bought him some food from the canteen. These felt like precious moments compared to his condition today. To expel the longing, he would go play and hangout with his schoolmates who live nearby.

Besides not being able to go to school, Maman could not do his routine physical therapy in di Rumah Sakit Kesehatan Mental Kabupaten Magelang. He usually does a weekly therapy, he now has not been in physical therapy for months, This will put his health in jeopardy if it is not solved. Routine therapy for children with cerebral palsy will support their motor skills. Even worse, there are no aid from the government regarding therapy for children with disabilities, according to Khoiriyah.

“If maman gets tired, I brought him to a masseuse as a last resort. At least the massage will help to reduce his convulsions so it would not damage his brain and reduce his mobility. I can only hope that the pandemic will be over soon so Maman can go back to therapy as usual,” she expressed.

Khoiriyah is thankful that Maman can still consume his medicines routinely every months with the help of PKDAC (Paguyuban Keluarga dan Anak *Cerebral Palsy*). The drugs are expected to prevent Maman's condition from deteriorating so he can still do his daily activities.

Khoiriyah once joined a training for basic physiotherapy specialized for each children so she could do her self-administered therapy with Maman. Khoiriyah is also a member of cerebral palsy family group. She can access information regarding the best treatments for children with cerebral palsy through the group. But the treatment in the hospital is still more effective according to Khoiriyah.

Khoiriyah is still grateful for receiving monetary aid from the government, especially the Rp. 600.000,- per month for three months from the ministry of social affairs. The aid helped her to fulfil the family's daily needs. Besides, PKDAC also gave groceries and other children necessities such as milk and biscuits.

Although the monetary aid that the government provided has not been able to patch the gap for the necessities, due to the high cost of having a child with disability. Besides, monetary aid are often short-term and can be exhausted easily.

" The governmental aid should be more specific to the family's background such as disability. Actually, many disabled citizens are registered in civil offices, whether in the Family Card of in disability organizations. Ofcourse thus can be utilized to the max by the government to reach all members of the community based on their specific needs. For example, routine aid for therapy for children with cerebral palsy such as Maman," she concluded with hopes. (*Bima2*)

A Long Step of a Teacher with Disabilities to Reach Her Dream

“I hope that the pandemic will soon be over so the students can come back to school. I thought that we can all gain some lessons from the pandemic that we have to be more aware of the many troubles of special needs education. Such as supporting facilities, curriculum, etc. With the published rule of PP number 13 of 2020 that should have gave a new hope to free people with disability in education matters,”

On a bright afternoon, a woman sat on her living room in a village near SLB 1 Bandung. With a cup of tea, she started to type something on her laptop. Her serious expression focused on to the screen. Almost a year she spent her time with her husband. Safrina Lofasita (35) and her husband Warno (35) both have cerebral palsy.

It has been six months since the COVID-19 pandemic hit the nation. Safrina, as she is called, teaches online classes. The teacher of SLB 1 Bantul started her story by her career journey until she became a teacher in SLB 1 Bandung.

Safrina revealed that her journey started when she became a teacher SLB Yapenas private school in 2010. Safrina undergone several selection tests with other aspiring teachers. She was thankful that she was accepted to the SLB Yapenas. Safrina’s way on to becoming a teacher was not lacking hurdles, she admitted to facing rejections from her colleagues. Many, especially her younger colleagues, underestimated Safrina’s teaching skills.

“I was grateful that my dreams of becoming a teacher is fulfilled. For me, teaching is a noble profession. Besides spreading knowledge, a teacher is also responsible for the growth of their pupils’ character. My achievement is not credited to me alone, but also to the support of my parents and my environment. Though I faced many discriminations, I thought of them as a training for mental strength, My most important job as a teacher in an SLB is to teach disabled students so they can become a generation that is beneficial for others,” she hoped.

It is unavoidable that Safrina may not have communication skill that her fellow teachers have due to her cerebral palsy. This was also the main reason as to why she was rejected. Safrina really had to fight against discrimination

Although Safrina taught in SLB that is familiar with disability issues, it does not automatically mean that she is accepted fully. With all of the rejection made her all the more challenged to prove that she deserves to be a teacher. She routinely evaluates her teaching methods, whether she does it herself or with other teacher help.

Marjani, the head of SLB Yapenas at the time was a big moral support for Safrina. Marjani kept on supporting and motivating Safrina. In 2015, she proved to everyone that she is capable of teaching.

After three years, in 2018, Safrina decided to register for CPNS. With her diploma of special needs teaching and a master of counselling, she registered CPNS in an SLB. There was a disability route at the time so it eased her way into employment. She got accepted to her job at 2019, and she was placed in SLB 1 Bandung.

Further, Safrina explained that in SLB 1 Bantul there are 5 types of different disabilities; autism, deafness, blindness, physical disabilities, and mental disabilities. Thus there are different teaching methods for different needs. The disability-based groupings make it easier for teachers. Safirah is now teaching four disabled cerebral palsy in second grade.

The challenges in teaching that Safrina felt is that when she will have to learn each student's characters. She values the importance of the students' character in determining a good study and teaching method. Although she teaches four students at the same time, she implements different methods depending on her students' abilities.

"There are students whose study methods is mostly through visual techniques, such as using pictures and videos. There are also students that utilize verbal technique through storytelling. The most important method for children with cerebral palsy is by using prompts, giving physical interventions to help students go along in their tasks. On the other hand, challenges in communicating between the student and the teacher is one of the struggles faced in the study process," she explained.

The online study due to the pandemic worsens this condition. Safrina is worried that the online study will lower the quality of student's recalling abilities, especially regarding independence and practical things in the daily lives, such as tying their shoelaces, wearing a tie, etc. Meanwhile other materials such as reading, writing, and math can be solved through parental or guardian roles.

"Thus parental role is crucial in re-explaining study materials so the students can understand it thoroughly. Besides, parents are hoped to be the catalyst of expanding children's potential in the free time outside of school," she explained.

Safrina now tries to educate parents, especially those of primary school students who are not independent yet at studying. "For some students, sometimes technical difficulties takes part in the study process, like bad internet signal. The government also has an important role as the policy makers to make affirmative decisions regarding the learning system," she clarified.

One of the touching thing that Safrina experienced was when one of the parents was patiently teaching their child how to wear socks. The child has cerebral palsy, thus activities with intense motor skills is a high-effort activity. Usually teachers taught these kind of things at school, but now the parents are filling in the role to be able to teach these skills at home

When asked about aids, Safrina explained that she and her students have received help regarding internet quota from the government, especially the ministry of education and culture. She thinks that it truly helped her and the students during the online learning. 4 gb of internet was distributed by BOS.

Unfortunately there are no specific help for disabled students, such as information regarding the pandemic and accessible self-protection equipment. The school initiated their own education regarding the pandemic through accessible informations, such as the right way of washing hands and things that are allowed and not allowed during the pandemic. However, the accessibility of self-protective equipments for the disabled are out of the school's reach, thus the need of government's attention.

"I wish that the pandemic would be over soon so the children can come back to school. I hope that through this pandemic, we can learn to be more understanding of the special needs education. Such as supporting facilities, curriculum, et cetera. Besides, the ratification of PP no. 13 of 2020 should mean as a new hope to freed the disabled in their education," she concluded.

Ups and Downs of a Therapist from Pakem

“As the pandemic goes on, I feel bad for kids that used to do their physiotherapy at the hospital or at home, now they are unable to do that. I am worried that this lack of therapy at the time will affect their condition. I am even more worried that their condition will worsen into the shortening of the muscles, dislocation, fluid retention, and the overall decline of their condition,”

A man wearing an embroidered shirt and a hat was taking off his shoes and headed into the mosque. It was 17.30 West Indonesian Time. With a soundsystem, he started to sing the afternoon call to prayer in Nurul Hikmah moswue in Pakem, Sleman, the sound echoes to the next village. It was his routine to join the congregation in that mosque.

After the afternoon prayer, the man sat cross-legged in the mosque hall and started his story. The man was no other than Slamet Basuki (27). Father of one, he rents a house with his wife in Dusun Tegalsari, Pakem, Sleman.

The baccalaureate (D3) in Physiotherapy from Universitas Pekalongan works as a therapist in Sayap Ibu foundation and does a housecall service privately. Five year since Jan 2016, being a therapist became his family's lone source of income. Slamet is also registered as an active volunteer in WKCP (Wahana Keluarga *Cerebral Palsy*) since 2016.

Slamet revealed that he goes to Sayab Ibu Foundation's home to practice therapy. As for housecalls, he accepts up to two housecalls in a week. 90% of his clients have cerebral palsy, and the rest has light to severe stroke.

According to Slamet, therapy is aimed to help train motor and sensory skills for each individuals. For example, an 11 months old baby should be able to walk. But if it had not, then the therapy will help the baby's walking skill. The therapy for cerebral palsy will be designed to suit how severe it is. For light to medium severity, the therapy is aimed to train and increase motor skills. While for severe conditions, therapy is aimed to prevent the worsening of the condition.

The principle of choosing whether to put the children with cerebral palsy to therapy or not is actually the same. The most important thing according to Slamet when doing therapy is to dig for more information about the child from the parents. This will allow the therapist to understand the condition and history of the child so it allows for a better direction in choosing a suitable therapy method.

When asked about the effect of the pandemic, Slamet admitted that his housecalls stopped for two months. This also affected his work in Sayap Ibu foundation. He only started to comeback to work to the foundation in mid-June. Ofcourse with the health protocol in form of a shift system in place, he alternates his working days.

Slamet did not receive any income during the first two months of the pandemic. Combined with the lack of aid from the government, he had to find ideas to survive without his income. Governmental aid only arrived when the New Normal period started in the form of a hazmat suit (PPE)that was given through Sayap Ibu Foundation for medical workers such as therapists.

“I was worried of the kids who used to get their physical therapy treatment in the hospital or at home, now they cannot do that anymore. I am worried that not continuing with the therapy would affect their condition. My biggest concern was how their condition could deteriorate through the shortening of the muscle, dislocation, fluid retention, and the overall decline of their condition,” he explained.

In May, housecalls started to trickle in again under the request of the parents of a child with cerebral palsy. Ofcourse under a strict health protocol, such as wearing a mask, PPE, and using hand sanitizer. IFI(Indonesian Physiotherapy Bond) also suggested the use of a few APD. Physical distancing will be implemented as long as possible, since the fact is that this can hinder the physical therapy process.

There has been an increase in demands for therapy, be it housecalls or in Sayap Ibu Foundation. Slamet thinks that it is due to the parents’ fear of accessing the hospital due to the rising number of COVID-19 positive cases.

The use of PPE especially a hazmat suit hinders Slamet from his therapeutic work. The movement of the children combined with the air not being able to escape from the suit would cause exhaustion, though he would always obey that rule to ensure protection for himself, for the patient, ad for their respective families.

Slamet often educates and gives tutorials regarding how to practice physical therapy for parents of children with cerebral palsy in hopes that the parents can start to do the therapy without the help of the therapists. He observes that this is highly important especially during the pandemic. Now therapy can be done online through WhatsApp groups consists of him and the parents of the patients.

Slamet would ask the parents to record the self-administered therapy of the children, usually one parent would do the therapy and the other would record. And then the video would be shared in the WhatsApp group where he evaluates them, and if he deemed that something was done incorrectly, he would send an input or a video tutorial of the correct way of administering the therapy through the chat. If the result was good, Slamet would suggest the parents to add some extra portion of physical therapy. Parents are able to reach him through WhatsApp if they had a question about the therapy.

“I learned of this type of method before the pandemi with a social group in Nanggulan, Kulon Progo with a BNB of parents of children with cerebral palsy. I visited them weekly from 9 am to 4 pm to administer physical therapy. I did that about the same time when I did the Sayap Ibu Foundation therapy and housecalls around December to February,” he explained.

Slamet told us of a touching story where he had a 10-year-old patient with hydrocephalus. The child was unable to sit in 2017 when they first started therapy, and was rather active that Slamet needed to have the child to trust him. Slamet came to the child’s house at 6 p.m and only started the therapy session at 7 p.m after they succeeded in persuading the child.

The child’s condition improved after a few therapy sessions. The child was able to sit, and at the end, goes to school. Slamet came into the child’s home for the routine therapy, and he was delightfully shocked to find out that the child had opened the door, indicating the vast improvement of their motor condition.

Finally, it was time for the child to undergo operation. The child’s condition post-op deteriorated, they needed to be revived, and ended up passing away recently.

“I was hit pretty hard by that, (especially after seeing) their motor skill and mental condition improved significantly. From the beginning of 2017 up to the operation in 2020. It took years to fight their condition. But God’s faith said otherwise, it might have been the best for the child,” he explained.

Lastly, Slamet also wants to give his appreciation to the parents of children with cerebral palsy with their unending patience in caring for their children. And to the government to pay more attention to the well-being of the physical therapists.

“I feel nothing but pride for the spirit of the parents of children with cerebral palsy, not everyone can handle what they are going through. And regarding my hopes, I wish that the government would help with developing free therapy. At least it will help ease the parents’ burden,” he ended.(bima4)

Fahri, A Child with Cerebral Palsy

“I regret ever getting angry at Fahri. I was feeding him and he spat the food out of his mouth. It pissed me off so I said ‘that’s why you should be able to feed yourself and not have someone else feeding you like this.’ That was when his tears came out. Fahri cried until he could not breathe,” Sukirman told us.

The brain is a vital organ that controls the human life. All system involving other vital organ (e.g the heart and the lungs) are controlled from the brain. So do thinking and movement

A damage in the brain (cerebral) would have an impact to the movement (palsy). Cerebral Palsy is defined as an abnormality of the brain, causing paralysis and loss of control over movement.

Fahri Aji Kurniawan (20) was 9 months old (Februari 2001), when the son of Sukirman and Surajinah has sudden high fever and convulsions. Fahri was brought to a paediatrician nearby. “The consultation costed 100.000 IDR. And then blood test and therapy. After an interview they gave us some prescription and ordered to go to the therapy. They gave us some prescription to be picked up in the pharmacy after an interview,” said Surajinah.

Fahri was then referred to Sardjito Hospital for some tests. Little Fahri then was diagnosed with Cerebral Palsy. According to the mother, Fahri was able to get up on all fours, and was able to roll over.

There was nothing that the doctor could do at that point. Twice a week little Fahri would go through a series of physical therapy. Growth therapy, occupational therapy, and physiotherapy. Over two years of routine therapy yielded nothing. Everytime the little boy wakes up, he would have seizures.

Alternative healing is the next choice. Not just around Yogyakarta, but also Magelang and Wonosobo. Whatever anyone said in hopes that the son would be “healed”.

“Wherever someone said that there is someone with skills I would come visit. On a motorcycle with Bapak, I carried Fahri because he was a bby. We did not care where we got the money, let alone the distance. Fahr can be healthy, he can be healed was out sole source of spirit. Six years of that effort in healing Fahri, but there was no change,” said Surajinah,

Come what may, they decided. They work together taking care of their son at home as a team. Always with a prayer so they would be given the strength to overcome every problems. “I have accepted that this is in god’s hands. This is fate,” said Surajinah.

A help is coming

After Fahri turned 11, attention came from many sides. In 2011 he received a wheelchair from the disabled organization UCP (*Unit Cerebral Palsy*). Fahri also receives monetary aid from the Kabupaten Sleman government through the social agency. Jaminan hidup (jadup) of Rp 300000 per month available once every three months.

All of these aids helped Fahri and their parents greatly. The aid received from Jadup is used to buy diapers. Fahri has to use diapers even in his age of 20 years old. He uses one diaper at night, and he does not use one during the day to save money, said his parents.

“Fahri needs to use three packs of pampers (diaper) 10 pcs each, Rp 73000,- per pack. So Jadup means a lot, it really helps us. Whatever shape of attention to Fahri. We give thanks and are grateful,”

In the last two weeks (end of august) Fahri received healthcare card BPJS kesehatan or Kartu Indonesia Sehat (KIS).

Fahri also received a therapeutic wheelchair from Ohana Foundation on Wednesday (2/9) and his family took it via an ambulance escorted by the wife of Sidoarum head of village.

“The help was very beneficial. We would be overwhelmed without it. I can take Fahri around although its only in the village,” Sukirman added.

They told us that they work together to give Fahri a bath. Fahri’s stiff body and his size makes it difficult to give him a bath alone. He uses a large plastic basin to bath.

Fahri uses pacifier bottles up until now. Fahri can only lay on his back so he is unable to drink without pacifier bottles.

Sukirman and his wife admitted to having hopes and worries about Fahri’s future. They asked for strength and to always be able to care for Fahri.

“I just ask for health, for strength, so I can take care of my son. Doa saya, hanya minta selalu sehat, selalu kuat, agar bisa selalu mengurus anak saya. Kalau bisa jangan lama-lama saya dan Fahri itu. Saya berdoa terus, kalau saya sampai tidak ada, supaya ada orang yang lebih baik dari saya yang mau merawat Fahri,” ungkap Sukirman.

“I also wish that the older sibling would take a good care of Fahri. My biggest worry is when Fahri has to go to the bathroom, while us as the parents are used to it, but what about other people?” he added.

Although they have BPJS, Sukirman said. “Hopefully we don’t have to use the BPJS because Fahri is healthy, “ he wishes.

Can not paralyze feeling

Although Fahri’s body is unable to do activities, he is in tune with his feelings. He can cry until he could not breathe when his father was angry at him. That was the only form of communication that he could do.

“I regret ever being angry at Fahri. I was feeding him when he spat his food out. I was annoyed so I said that “this is why you should be able to eat by yourself, so no one else had to feed you”. Then tears came out, Fahri cried until he could not breathe, Sukirman told the story. Sukirman deeply regretted this and has not been angry at Fahri ever since.

“If Fahri could choose, he would not want to be trapped in his disability for the rest of his life. He would not want to not be able to eat by himself either. I have to be more patient in taking care of him, be more understanding. It is so sad to see Fahri cries until he could not breathe,” he revealed.

Sukirman can see two sides of the story. Him not being at work means that he is able to focus on taking care of his son. On the other hand, he had lost his job as a worker in PG Madukismo since May 2020.

Surajinah still sells cooked and raw vegetables. Since neighbourhood entrances are closed, she is too affected by the pandemic. Usually she made her rounds at 11 am to 2 pm.

Fahri could not do anything at 20 years old. He could not speak, he could not walk, nor could he speak. He can only communicate by crying. His skinny body lays on a bed on the floor behind the food stall, so it would be easier for Surajinah and Sukirman to take care of Fahri.

Surajinah is a housewife who sells vegetables on the side. Besides selling the vegetables from her stall, she often make rounds around her neighborhood. She would wake up in the morning to sell vegetables on the market, and then she would go home to feed and bathe Fahri while attending her stall. And then around 11.30 she would make rounds selling vegetables after feeding Fahri. Surajinah adalah ibu rumah tangga yang juga berdagang berbagai sayuran.

As her husband had thought, Surajinah believes on the positive and negative side of the pandemic. As her husband takes care of Fahri full time so she can continue working, although many neighborhoods are not allowing sellers to get in, thus the declining sale of her vegetables.

“But it is ok. I am not the only one affected anyway. We would just have to go through it. Although my husband is retired and I don’t get as much sales as I used to, we can still feed nutritious food to Fahri. We can still call a doctor if Fahri is ill,” Surajinah ended the conversation that Saturday afternoon (5/9).

The Pandemic of Covid-19 Taking Dreams of a Child with Cerebral Palsy

The wish is that the pandemic would be over soon. During the pandemic, my husband's salary decreases. Before the pandemic, he serviced seven clients over night, but now less than 5 clients and not every day.

The threat and spread of COVID 19 spares none. No matter what country, state, social status, sex, nor age. It threatens the health, the soul, the life. Economic destruction looms near, especially those who had lost their job, who could not continue to work. The threat of poverty never plays around.

What about children with cerebral palsy? The pandemic threatens and robbed their dreams. They lost access to therapy, an integral and necessity need for them.

According to sources, cerebral palsy, or the paralysis of the brain causes disruption to movement and coordination. This could happen while a person is still the womb, or during the birth, or the first year of life.

Stiffness or limpness of body parts are signs found in children with cerebral palsy. Thus, physical therapy is needed to ensure and maintain the growth and use of body movement.

Oktaviano Dwi Kurniawan (12), born on October 21st 2007, the second son of Sugiarto and Nuryatin, is losing his access to physical therapy due to the COVID-19 pandemic.

Due to lack of therapy, his legs which were able to step flat, now are on their tiptoes and stiffens when he stands up. Okta's hands, neck, and spine are also declining in their functionality.

The routine therapy was done in the hospital in the last six years. Twice a week, Nuryatin brought Okta to Sardjito Hospital. She bikes to the hospital in the early morning while carrying Okta when it is therapy day.

The old bike took them to the bike park in Piyungan 3 kilometres away from their house for two years. Next, they would take a bus to Gedong Kuning, and then another to Sardjito hospital.

The trip to the therapy takes at least two hours. After taking care of the administration, it takes three to five hours of waiting for 30 minutes of therapy. They would be back home in late afternoon, but the hope of their son walking and being independent one day wipes away the physical and financial fatigue.

The duration and cost of the trip were shaved off when they bought a motorcycle in 2016. But misfortunes were unavoidable. October 2019, not so long until Okta's birthday, their two-year old motorcycle was lost when it was parked in the hospital's parking lot when they were waiting for Okta in therapy.

They had to let that go. Unwilling to complicate things, Okta's older sibling ordered a go-jek from their office. The kind Go-jek driver refused to be paid when they found out what happened to Nuryatin.

"It costed IDR 41000,-. They had to fill up the gas. I tried to pay for the gas, but they refused. They said that they just wanted to help. Although his family is also waiting to the wage from Go-Jek. He was from Wirobrajan, his name was Mr. Rohadi," Nuryatin told us.

We did (Okta's) therapy for four years in Sardjito, and then two years in RSUD Prambanan. The cost was covered by BPJS," Nuryatin explained.

Please walk, my child

Nuryati has a strong willpower. She knows no tiredness, nor she ever thought of giving up. They realize how important Okta's therapy is despite their limited condition. They decided to call the therapist to their house. "(We are) building a new hope," they said. Okta's therapy schedule is once a week every Friday. Each therapy session costs IDR 100.00,-, and Okta have done two sessions in August 21 and 28.

"I just want Okta to be able to walk, to be able to speak. I have this resolution, that when Okta is able to walk, I would slaughter a goat. Please, walk, son," Sugiarto wiped his tears.

The pandemic did not just took Okta's therapy away, but also lost Nuryati her job. Her office was out of operation since April, and she was fired. She survived only with her husband's wage.

When they were both working, they shared the responsibilities of taking care of Okta. Morning until Afternoon Nuryatin would go to work, with her husband taking care of Okta. When she got home, Nuryatin would take care of Okta while Sugiarto would work as a masseur. Making rounds to his customer's house on their granny bike.

Sugiarto works as a masseur from the afternoon until morning. In a night he would have 5-7 customers. He is paid between IDR 10000,- to IDR 50000,-, though sometimes some customer would not pay.

"As long as I can help, it is ok if someone could not pay. When someone asked for a massage, I would still do it even though they have not paid (for the last session). There are 3 people who have not paid until no. It is ok," said Sugiarto.

Need struggle

Life is easier to fight for with positive hopes. That is exactly what Sugiarto and Nuryatin are doing. Okta was born ten years younger than his brother, who was a healthy boy with no health problems.

Okta was diagnosed with cerebral palsy when he was 9 years old, in July 2008. He was taking his vaccination in the local health centre Prambanan, when he had seizures. He was then rushed to Panti Rini hospital in Kalasan, where she was treated for 4 days to no avail. Due to monetary issues, Okta was taken home.

"4 days of treatment with no improvement, and we already used 1,8 million IDR, and we do not have money, nor BPJS insurance. I fought to take Okta home. I strapped him on my back, and we cycled home. It was the hottest time of the day," Nuryatin told the story.

Before the diagnosis, Okta was able to toll over, sat, and had started to crawl. When Okta was a baby, the family was not covered by insurance yet. So when Okta had to be hospitalized they had to pay the cost themselves. They obtained Kartu Indonesia Sehat (KIS) and BPJS in 2000, and Kartu Peserta Keluarga Harapan in 2016.

The Sugiarto-Nuryatin family lives in Dusun Beran, Sumberharjo Village, Prambanan. In a modest house of 4x6 m built with monetary aid post-Jogja Earthquake 2006.

Not every part of the floor is tiled. Their kitchen still has dirt. The fear of monitor lizards coming into the house and disturbing their son, who is usually laid on the floor, made the decision of putting in tiles, although they only put it on the living room and the bedroom using a loan from the bank

The family also does not have their own bathroom. They are using a communal bathroom with 7 other families, built as a post-earthquake aid. Sugiarto built a ramp for Okta's wheelchair on the frontside of the house.

Okta has two aids, two wheelchairs. One was from UCP which now has flat tires, and one with arm support to be used during therapy sessions from Ohana Foundation. There are also therapeutic shoes or Ankle Foot Orthosis (AFO), given by WKCP (Wahana Keluarga Cerebral Palsy). What he needs right now is a mattress and a large bolster to help in the process of physical therapy at home

Her last wish was to have the pandemic to be over asap. So the family can go back to normal. During the pandemic, her husband's income from being a masseuse is reduced. He used to have 7 customers in one night, but now he can only have around 5. And that is not even everyday. Nuryatin, a member of the WKCP since 2012 concluded. (*ning2*)

The pandemic and Problematic of Distance Learning System

“Learning online is really unsuitable for me, also for my students who are deaf, especially those who are double handicapped (deaf and low vision). The aim of education is for an improvement in cognitive, affective and psychomotor aspects that are not (currently) maximized” said Ms. Fatin.

Indonesia and the Special Region of Yogyakarta (DIY) in particular, entered in September 2020 the sixth month since a physical distancing policy was implemented to avoid the spread of the Covid 19. In the education sector, during the Covid-19 pandemic, distant learning became method of choice. Students do not go to school, but learn distance through online media or online learning.

The online learning policy has been in place since the end of the 2019/2020 school year and continued in the new school year 2020/2021. Like it or not, this policy must be implemented to avoid the spread or spread of the virus that is sweeping the world today.

It is undeniable that the distant learning policy presents problems to many parties, more specifically the students. Not only the physical condition, the psychological or mental condition of the students is much more affected. The reason is the sudden implementation of online learning may have challenges, especially due to previously unidentified conditions.

Tuesday (1/9), Rizqi Fatin Saffanah, usually called Ibu Fatin, teaches 4 students with different hearing abilities (deafness). One of the four students also has a low vision and can only see at close range and in bright light. One of the students, Hayun, has multiple disabilities (deaf and low vision). The other three students who are deaf are, Zidan, Taayun and Susi.

In the new school year of 2020/2021, Mrs. Fatin happened to teach a new class of students who she had never met before. So they have never had physical contact with students in the class. By itself she could not assess the learning needs, nor did she know the background of the four students.

Assessment Function

For Mrs. Atin, an assessment is essential. Because the results of the assessment are used as a reference for preparing appropriate learning methods for each student. Remote learning is a challenge for Mrs. Atin. Apart from not understanding the needs of various students, she also did not know the psychology of students. Moreover, she did not know the socioeconomic background of the family. She admitted that she had not been able to find the right method for her four students.

The material submitted online encountered various obstacles. There are students who do not have cellphones, some have problems with quotas (credit), some whose parents are busy and cannot be there. There is also a student who could not participate in online learning because he has low vision.

During online learning, the material presented is modified. Not only arithmetic and writing (normative), but also in the form of tasks to be carried out in daily activities, like the washing of clothes by yourself, for example. However, for Fatin's mother, online learning success cannot be

measured. Not only success in the form of getting numbers on paper, much more important is the change in attitudes and behavior of students. Those cannot be obtained by learning online.

In fact, the average student has reached the point of saturation and stress. The stress of not being able to meet with school friends, being stuck at home, not getting full support from parents. This negative impact was seen in one of the double handicapped students.

Due to deafness and low vision, Hayun received a slightly different learning method from the other three friends. One a week he gets a home visits, once a week week he receives face-to-face lessons at school. Different learning methods are applied, because Hayun needs a different way of learning.

“The method of touching is the most appropriate method for Hayun. For that, I applied a slightly different method from the three friends. If the others go through online media, I add Hayun face to face once a week, ”explained Ms. Fatin.

There is an idea to implement the material in the form of a game that involves families. With the hope of being able to fill the fun needs of her students, but constrained by facilities and infrastructure, as well as knowledge. Because of this, the zoom application is needed.

Must go to school

“Studying online is really not suitable for me, also for my students who are deaf, especially those with double handicaps (deaf and low vision). The goal of education is that there is a process of change in cognitive, affective and psychomotor aspects that cannot be maximized,” said Ms. Fatin.

She continued, “So you have to go to school. No other way about it, go to school. Let’s get rid of the corona virus together. So that students can study at school”, she said.

The application of distance learning by means of an online system or in a network (online) has a serious psychological impact on students. Support from parents, teachers, and fellow associates is needed so that students won’t become stressed (depressed). The psychological impact is different from one student to another. It depends on the communication patterns between parents and children, teachers and students through assignments, as well as with fellow friends.

School is a gathering place for children from various walks of life and various family conditions. Schools have an important influence on children’s development, especially in their social development. Interaction with teachers and peers at school, provides great opportunities for children to develop cognitive abilities and social skills, acquire knowledge about the world and develop self-concepts throughout middle and late childhood.

Students spend 6-8 hours at school. During which they can study in groups, make friends with various characteristics, understand the teacher as authority figures and get along in the school environment. Interaction with friends at school will teach about cooperative behavior, friendship, help to help, competition and social skills in the future.

With the policy of online learning, students cannot interact with their peers, as well as teachers, although cognitive abilities and social skills can be built by the interaction of students with their families. However, it will be a problem if the interaction between parents and students does not occur or parents do not understand the child’s learning material or with technology that is used as a learning tool so that the child has difficulty asking for help from his parents and is reluctant to learn. (Nining3)

The Struggle of a Child with Cerebral Palsy

Her husband, who works as a *homestay* administrator, now only receives part of his salary due to the impact of Covid-19. All tourism in Yogyakarta are closed causing *homestay* visitors to be absent. Several employees had to be laid off, making Artati's father to be on guard for 24 hours. Seeing the state of her two children who could not be left behind, finally Artati's mother decided to move in to her husband's workplace.

It doesn't feel like we have entered already the 6th month of the Covid-19 pandemic, and we still don't know when this pandemic will end. Moreover, instead of decreasing, Indonesia has experienced a significant increase in cases. Especially in Yogyakarta, number of cases increases rapidly, plus not all of its hospitals can handle Covid-19 cases.

This has an impact on access to several public health services which have had to be stopped due to the spread of the virus in the hospitals meant for Covid-19 patients. For example, Sardjito hospital was designated as a Covid-19 referral hospital because the medical equipment available. In addition, Sardjito also has other health services such as a children's health polyclinic that provides various kinds of healing therapies. Examples of some of the therapies provided by the polyclinic are physiotherapy, occupational therapy and speech therapy.

This therapy is specifically of importance for children who have motor neurological dysfunction, like a child with cerebral palsy. Children with cerebral palsy have different physical conditions from children without cerebral palsy. The physical condition of children with cerebral palsy will be different depending on the level of their condition, but most children with cerebral palsy are unable to move freely (Maimunah, 2013).

Cerebral palsy is not a life-threatening disease, but a condition, unless children are born with very severe cases. Children with cerebral palsy will experience motor problems due to damage to the brain tissue, especially in the motor center or connective tissue (Eliyanto & Hendriani), 2013). The prevalence of cerebral palsy in developed countries is estimated to be 2 to 2,5 cases per 1.000 live births, while in developing countries it is around 1,5 to 5,6 cases per 1.000 live births. In the USA, it is estimated that there are more than 500.000 sufferers.

As an example, Zaid Abu Bakar Musyid (5), the first son of Artati who was born on November 5, 2014, and has cerebral palsy. Because of this pandemic, the therapy that he had received for the last 5 years had to stop. Two months after the pandemic began, Zaid stopped doing therapy, his legs, which were previously able to crawl quickly, are currently stiff and difficult to move. Likewise, the neck, hands and spine also experience decreased function.

Previously, when Zaid was 6 months old, his family didn't immediately take him to the doctor but to a massage shaman because they thought it was just a normal growth delay, "We are Javanese, so we thought that this was normal. He was only 6 months old, so we took him to a massage," said Mrs. Artati. .

However, after several attempts to improve the growth of her baby, nothing worked. At the suggestion of his brother, Zaid was finally taken to a doctor. Zaid was diagnosed by the doctor with an unusual disease. The doctor then referred him to a large hospital (RS Sardjito). From there the beginning of their struggle began. Ms. Artati and her husband started to administer BPJS cards (the social security administering body) to help carry Zaid's medical expenses.

At the end of 2015, Zaid began doing therapy at the Sardjito hospital. His enthusiasm to be able to walk like a normal child was generally very high. Seeing his friends around the place where he lives raises a question addressed to his mother "why can't I walk yet? Why?" he asked curiously. This made her mother's mind burden about her child's psychological worries, Mrs. Artati patiently explained slowly, "Mas Zaid has cerebral palsy, it is a developmental delay, and then I showed him his pictures as a child, this is Mas Zaid when he was treated" said Artati. Two times a week, Artati took him to the Sardjito hospital for therapy.

At the age of 2, Zaid began to sit up and his neck bones became stronger, coupled with growing teeth. Zaid's progress began to appear as therapy progressed. Zaid has a younger sister who understands his shortcomings. Since childhood his younger sibling has been given the understanding that he was born different from other children. Zaid got excited by his younger sister and wanted to get up and run like his younger sister does. This makes Zaid's parents strong because they see his high willingness to be able to recover from this disease.

At the age of 4 years, Zaid was able to crawl with both hands and slowly used his knees "he was 4 years older and crawling fast, until his knees were squeezing. Even though he didn't know the important technique, just so quickly, he was just getting old. For the past 5 years, he has learned to crawl with crossed knees," said Mrs. Artati, telling her child's story.

Seeing the decline in the child's bodily function due to the cessation of therapy during this pandemic, Mrs. Artati then took the initiative to seek home care physiotherapy. For a month and a half, Zaid did receive home care physiotherapy. That was a very significant development. Mrs. Artati felt a very big difference when therapy in Sardjito used BPJS and homecare physiotherapy at her own expense.

"If you use BPJS, it's different than at your own expense, the handling is different, in the hospital, it's 45 minutes, for talking, filling in data, calling the patient for about 10 minutes, then the longest session is 30 minutes. Parents have been called, after this Covid home care therapy there has only been 5 meetings. Zaid has been able to crawl on to a chair, sit alone in a high chair, even though previously he was afraid, he thought that he was about to fall off," Mrs. Artati explained.

Especially during this pandemic, after the therapy room in Sardjito was declared a green zone, Zaid was able to access his therapy again, but Artati was disappointed because there was only one therapy that could be accessed, even though previously she received three therapies, namely, physiotherapy, speech and occupational therapy. "During this pandemic, Zaid only received only physiotherapy. I don't know how long he only got one," she added.

Life always needs struggle. That was the persistence of Zaid's parents who always strive for the recovery of their baby. This pandemic requires Artati to find additional money by selling online to fulfill her family's needs. Her husband, who works as a homestay administrator, now only receives part of his salary because of the impact of Covid-19. All tourism in Yogyakarta is closed since homestay visitors remain absent. Several employees had to be laid off, making Artati's husband have to be on guard for 24 hours. Seeing the state of her two children who could not be left behind, finally Artati's mother decided to move in at her husband's workplace.

In his current residence, Zaid has several aids. One of them is a great trainer from the Ohana Association. Zaid was not given a wheelchair because of his willingness to walk high, to minimize laziness he was given a trainer. Another device that he has is a wheelchair which he got for personal expenses, but unfortunately the wheelchair cannot be used anymore, because it is too small. To maximize therapy, Zaid also has therapy shoes or Ankle Foot Orthosis (AFO). He received those from the Asian Friends Association, but these shoes cannot be used anymore because they are too narrow.

Their one hope is that this pandemic will stop soon. So that Zaid can carry out therapy according to his needs as he had lived before the pandemic. (Risa1).

Educational Problems for Children with Cerebral Palsy

"Tired of being at home, my schoolwork is difficult to understand," explained Azzam when telling his complaints during this pandemic. The tasks given by the teacher may be very easy for normal people, but it turns out to be difficult for Azzam. "He has to call things, to count, to know the name of things, and to record them and send the recording to the teacher"

At present, education is a priority for most Indonesian children, especially the Special Region of Yogyakarta (DIY) which is already known as a City of Students. Now all people, rich or poor, "normal" and "disabled", are provided school facilities by the government in their respective regions. However, since the pandemic our education system has had to change. Everything "from home", including school, and this is not without new problems. There are still many students who find it difficult to take part in distance learning, including students with disabilities at the PGRI Minggir SLB, Sleman.

Sleman is one of the districts in the Special Region of Yogyakarta (DIY) that has provided a forum for persons with disabilities to claim their rights to get the same education as people in general. SLB PGRI Minggir, is an extraordinary school that was established for those with disabilities to get a decent education and in accordance with what they need.

Thursday (2/9), Muhammad Azzam Prihantoro, a PGRI Minggir SLB student, as well as a child with cerebral palsy, along with Diana Ani Suryani (his mother) shared the story of his condition during the pandemic. The first son of a married couple, Diana (39) and Gunawan (42), suffered from cerebral palsy after birth and was diagnosed by the doctor that there was a part in his brain that had not yet been fully developed. Thus Azzam (18) cannot grow normally like other children.

Azzam has been doing therapy since he was 6 months old. He has made various efforts since 18 years ago for the recovery of his baby. From coming to various places where traditional healers get massages, then to a neurologist in Solo, to big hospitals such as Sardjito and Bethesda. However, it has not delivered significant results. But with the persistence and optimism of both of his parents, Azzam managed to sit down without help when he was 1 year old, and little step by little step progress began to appear. He also started to speak at the age of 1,5 years old, although his speech is not clear.

But despite his physical limitations, Azzam has a high willingness to learn. Seeing the potential of their son, Azzam's parents decided to send him to school. Azzam was registered as a student at the Minggir Special School (SLB), Sleman starting in 2009. With the help of a wheelchair that he got from the Wheel Cerebral Palsy Unit for Humanity (UCPRUK) Yogyakarta. Diana and Gunawan entrusted their son's education to the school. Due to limited mobility to always carry the wheelchair that he uses at school, they finally decided to leave it with the school.

Azzam showed that he was very happy to be able to go to school and socialize with friends with different limitations. He also shared that at school they help each other to do many things "at school my friends help each other. The one who pushes my wheelchair are sometimes my friends who are

blind who takes me to the canteen to buy some snacks," stammered Azzam. In this case, Azzam's parents are sure that their son really enjoys living his days with his physical limitations.

Azzam has 2 sisters who were born normal and healthy. Seeing that their two daughters were born normal, Diana and Gunawan had to treat their three children fairly so there would be no jealousy among their children, but the facilities they provided still had to be suitable for each child's needs. Azzam began studying in a kindergarten near his home, before continuing his studies at SLB PGRI Minggir. In determining the school, Azzam was given the freedom to choose which school he liked. That choice fell at SLB PGRI Minggir, "I felt that this was the right choice, the place is nice, lots of facilities, comfortable too" added Azzam in a voice like a person shivering because of his illness which makes tremors if he is too excited to tell stories.

Limited mobility and a long therapy process made Azzam feel bored, so he chose to go to school instead of continuing therapy. It cannot be forced. Diana has the principle that "the important thing is that Azzam is happy, comfortable and feels not burdened" as she explained with an optimistic face. Diana (39) shared that school was the alternative she chose because of her son's happiness. She admitted that she was happy to see her son socializing like children in general, "if I am my son, it is not smart, the important thing is happiness, meeting many friends. I fulfill his educational needs, just like her siblings who are also at school," explained Diana with an optimistic face.

Now he is in grade 2 of high school, in the same school since 2009. During this pandemic, he found it difficult to follow distant learning. Azzam also admitted that he was bored because he could not meet his friends. "Tired of being at home, my schoolwork is difficult to understand", explained Azzam when telling his complaints during this pandemic. The tasks given by the teacher may be very easy for normal children, but it turns out to be difficult for Azzam.

In addition, Azzam has sensitive breathing problems which makes covid-19 extra dangerous for him, so during this pandemic Azzam did not leave the house at all. Feelings of boredom sometimes make him uncomfortable, causing stress, but his parents slowly gave an understanding of the impact of the virus that occurs when it attacks the human body. With this understanding, Azzam began to understand that the rules for staying at home were the only solution to prevent the spread of the virus.

During school, he was not taught to read and write, because of his physical limitations which made it difficult to reach reading materials and difficult for his hands to hold writing instruments. Despite these shortcomings, he always feels more fortunate when he sees his fellow schoolmates with disabilities who are more physically limited, for example, some of his friends cannot see, some have mental retardation (Grahita) so they are unable to think, and there are many other. Seeing this diversity, Azzam has a high social sense to help others during any kind of activity at school. SLB PGRI Minggir, has 30 teachers with a maximum of 5 students per one teacher. It aims to maximize the delivery of material to students.

During this pandemic, his daily life was limited to playing with his younger siblings. In addition to playing, he also worked on tasks given by school together with his mother. There is no other activity that he does. It can be said this distant learning system is very influential on children's psychology.

Azzam hopes to be able to go back to school, because for him school is a place to have fun and gather with his friends. Even though he only meets them 6-8 hours, it makes him happy. Diana (39) hopes that this pandemic will end soon so that her son and daughters can go to school as usual, because distant learning also makes it difficult for her because she has to teach the material provided by the teacher at her school. (Risa2)

Difficulty in Therapy for Children with Cerebral Palsy

According to (Clark 1964, in Sriwidodo, 1985), cerebral palsy is a condition of damage to brain tissue in the motor center or connective tissue, which occurs during the prenatal period, during childbirth or during the process of central nerves formation, characterized by paralysis, paresis, impaired coordination. or motor function disorders.

Children with cerebral palsy will experience disturbances in their movements. Cerebral palsy affects muscles and a person's ability to control them. The muscles of a child with cerebral palsy can contract excessively, or very little, or all of them at the same time. The limbs can become stiff, forming strange positions. Fluctuating muscle contractions can cause limbs to tremble, wobble, and cling. Cerebral palsy can also affect balance, posture, and coordination. Activities such as walking, sitting, or picking up an object can be difficult. Children with cerebral palsy also have the potential to experience other disabilities such as intellectual impairment, seizures, vision and hearing problems.

Anwar Khoir Taufiqurrahman, a boy from Magelang Regency, who is 12 years old, was diagnosed by a doctor with cerebral palsy since he was a baby. Today, he is unable to walk and cannot speak. His parents have taken various kinds of efforts since Anwar was not yet one year old. He has visited all major hospitals, they have also visited several neurological clinics, but God has a different wish, Anwar has not been allowed to walk and talk, not even to sit.

The married couple Muhardi (56) and Sudiasri (54) are Anwar's parents, who live in Ngluwar Regency, Magelang. Both parents are very concerned about the health of their children. Their persistence during the treatment for their son touched my heart. How could they not, they were willing to leave at 4:00 AM in the morning to the nerve hospital in Solo for the treatment of their child's therapy. Unfortunately the treatment did not last long, due to limited mobility and the time they finally chose to end the treatment there.

Without giving up, Muhardi (56) and Sudiasri (54) continued the treatment in Magelang. Upon a referral from a neurologist, they finally went to Dr. Soerojo hospital in Magelang. With the help of the cerebral palsy children association in the Magelang area, it is easy to access doctor's schedules and therapy hours at Dr. Soerojo hospital. Access to get assistance has been greatly facilitated since he joined the association.

Anwar's daily life is playing with gadgets on his back or on his side. His physical limitations prevented him from being left alone for long. When his parents worked, he was waiting with his mother's younger brother, so that he watches and supervises Anwar's activities at home.

Sudiasri said that Anwar was a child who was difficult to socialize with, "he cries when he meets a lot of people. He doesn't know what to do, he's embarrassed. Basically he is crying and wants to go home, so I carry him to the field so that he would not see as many people" , explained Sudiasri.

Sudiasri also told Anwar's condition made them stop therapy since a year ago. This was chosen because of the difficulty in managing time and constraints in mobility. The process for one therapy is very time consuming, starting from travel, administration process to queuing for self-therapy. For years he did the therapy but the results were not significant, which made them chose to stop.

Relief came when Sudiasri received information that RSJ Dr. Soerojo hospital provides a fixed schedule for therapy for children with cerebral palsy in the Magelang area through the association he has been participating in for a long time. With this new policy, Anwar's parents decided to resume the therapy so that their son's condition could improve.

For approximately one year after Anwar stopped therapy, his parents took the initiative to make a simple therapeutic aid to replace the therapy they had ended. Anwar used to have a wheelchair, provided assistance from the humanitarian agency for the cerebral palsy unit (UCP) in Yogyakarta, but the wheelchair could no longer be used because its leg support was damaged and could not be repaired. The damage to the wheelchair meant that his parents had to carry Anwar wherever he went.

The decision they made to stop therapy one year ago could not be separated from the lack of therapists in the area where she lived. "There was a therapist in the health centre in Balerejo, so I took hm there because it was close instead of the mental hospital, she was a good therapist, but because the therapist is pregnant, so she stopped working, now there are no therapist at all there,"

The hope of his parents that was conveyed to me is the addition of therapists to the Magelang area, especially to Ngluwar regency, where he lives now. This would make it easier for him to obtain a more optimal therapy. In addition to saving time because he would be close to a therapist, he felt more optimistic when he did therapy at the health center a year ago.

Due to the considerable work of Anwar's parents, he did not have much time to do therapy in the hospital. He shared that he wanted to give Anwar physiotherapy besides home care, but again, the lack of therapists in the area made it a problem and so far there was no solution. (Risa3)

Less Information Making Us Could not access Anything

Aqila Azmia Sahasika, 2,5 year-old a toddler with a CP (Cerebral Palsy) disability. Aqila's parents learned that their baby had been infected with the virus when she was 4 months old. She had high fever and convulsions. As a result of the infection, the child has blockages in his motor nerves, leaving both parents shocked and devastated. Especially, the father who has high expectations for our daughter and his first child, seen by the frequent times the father sat in silence while carrying or with her, there are streaks of sadness and disbelief in all he experienced.

Several treatments were carried out, starting with visiting a healer and a massage clinic recommended by his brothers and sisters. Not only in Yogyakarta, but even outside to the countryside which obviously requires a lot of time and money. Of course medical efforts with routine therapy by using BPJS in Mandiri. Hope for recovery is so intense for both parents that they apply all the financial resources available to them. Routine therapy is done 2 times a week for years but has not shown any results, while finances are running low. The mother, who at that time was an honorary teacher at a madrasa, finally had to volunteer to resign in order to accompany the baby to therapy independently at home .

There is not much to do other than just provide routine therapy at our own expense. There is no information whatsoever to help solve this problem, the tendency of parents to have "different" views and not socialize makes them not get any information. The search for information that is obtained, is more on ways of therapy and treatment, but rather it has not yet reached whether there is an institution that can help ease the financial burden in conducting therapy, or to community groups who have the same problem so that they can strengthen each other and find solutions together.

Since resigning from her job, the parents then made a restaurant as their main source of income so they could accompany Aqila directly in her daily life and during therapy. But during the Covid 19 Pandemic, the culinary business was closed because it was not selling well, no one came because of the fear of being infected with the virus if they met many people especially their children were in a vulnerable condition. They choose to return to their mother's house and live by relying on their savings.

At this age, Aqila's development is very slow, both gross and fine motor skills. When children of the same age become interested in the toys that are provided, Aqila has not been able to respond well. His favorite activity is just watching TV, and when turned off she will cry.

The treatment that was carried out for Aqila was hampered because the parents did not dare to bring her to the hospital for therapy. Fear of bringing them to the hospital and taking a long time to get therapy rations made both parents choose therapy independently by calling the therapist home when they have more money available, because once the therapist comes they need RP. 100.000 - Rp . 150.000 . C scent expensive for the family that if this has to be paid 2 times per week.

Aqila's family is a closed family, so they never bring Aqila to socialize with the surrounding community. So that often Aqila gets scared when she hears a loud voice or a very loud voice.

During the Covid Pandemic, they finally received assistance from the Government in the form of B L T (Direct Cash Assistance) of 200.000 for 6 months which had been received for 3 months. It was

quite helpful, he said, especially when there was no permanent job. As well as assistance from the local health centre in the form of PMT / Supplementary Food Program and from the Puskesmas in the form of bread and milk

Aqila, a connoisseur of the Upin Ipin film, who is actually in need of intense assistance, both medically and psychologically, with habituations that will make her independent according to her abilities. **(krisna1)**

Aulia Abidalah, A Child with Crebral Pasy Loving Music

Aulia Abdilah is the name given by her parents, so that it is easier for people to know and be recognized by people, but it seems that what they dream of won't go according to their expectations. Aulia who was born when her mother was 6 months pregnant on February 24, 1998 in Jakarta. Little Aulia was born with a condition which was caused by premature birth and had an impact on motor nerves which later made her a CP disability.

One statement from the doctor who said Aulia would never be able to walk encouraged both parents to try various kinds of therapies since she was a baby in Jakarta . And to this day they moved domicile to Yogya and are still doing therapy. The place of therapy varies from massage clinics recommended by relatives and neighbors to hospitals that have quite a reputation. Not infrequently when there is good fortune, they will invite the therapist to come home with the hope that the results will be better. However, the therapy that has been going on for years and they spent a lot of money. The situation worsened when little Aulia suffered from German measles, which treatment turned out to have an impact on the therapy process being carried out.

Aulia is very close to her grandmother because when she was not even 2 years old, she already had a younger sibling, so automatically aulia's care was taken over by her grandmother. The separation of the two parents, where the father left the family, made the family condition even more difficult so that the burden of caring was mostly done by her grandparents. The real love she got from his grandparents, especially after her mother remarried and had children. Aulia's daily life with her grandparents starts from teaching independence to delivering school. Little Aulia grew up with the love of her grandparents but was not taught to interact with the community. Until today Aulia often doesn't want to be invited out of the house and doesn't want to meet strangers.

While still studying at SLBTP she was classified as a person who was quite active. Many of the activities she participated in such as music and writing classes, her memory skills were very high. It was proven that when she was still in school, she was rarely seen writing what was taught but when asked she would be able to explain in detail what was conveyed by her teacher. Her ability for observations is also remarkable. It is proven that she can distinguish who is coming only from the sound of a motorbike or by voice. Her love for music, especially in listening to songs, made her family look for lots of songs for her daily friends, only then would Aulia sing along to the music. The songs she liked were not from a specific genre as well as she likes in collecting the t-shirts she owns. Even so, Aulia still needs other people's help such as for eating, bathing and dressing.

The move of his parents to Yogyakarta due to job made her no longer able to carry out routine therapy twice a week, because the health insurance they had was only from BPJS Mandiri which was unable to cover all therapy needs. So since a year ago, Aulia hadn't done any therapy at all.

The covid pandemic has not changed Aulia's activities much, because she is uncomfortable and shy with strangers, making her only do activities at home. The living environment which is in the green zone also presents its own relief given the vulnerability that diffables have during the Covid 19 pandemic.

The family's acceptance of the circumstances and limitations makes Aulia able to receive good parenting, but it still needs learning so that she is willing to interact with other people without the shame that she often shows when meeting new people. The surrounding community is quite friendly. There is no stigma and often provides good moral and material assistance. Their parents have not been able to use those to make Aulia who actually has some potential to be involved in every moment.

The rented house that Aulia lives in is not yet accessible to her, the land and stones in front of the house as well as a small ditch are obstacles when the family takes her out of the

house . The unavailability of *ramps* for her wheelchair is also an obstacle when she wants to get in and out. Luckily, Aulia recently received mobility assistance in the form of a wheelchair from Ohana, which made it easier for her to do her activities.

The impact of the pandemic on the family's economy is quite big. Aulia's father works as a project supervisor while in these conditions it is very difficult to carry out the job. Besides these jobs are not a source of stable income each month. According to Aulia's mother, when there are no projects, they use up their savings that they have. It happens that they have to be very careful with their spending, because there are sic members of the family. While waiting for earnings of the husband, the mother of Aulia works as a reseller, for an additional purchase daily necessities. This job was chosen because in order to stay at home to accompany Aulia. The totality that he dedicates to his child deserves a thumbs up because not all parents can do the same , even a few who cannot accept the child's condition. Even so, deep down there is sadness, but still try their best for the good of Aulia, such as teaching skills lessons and so on. Although it is often less acceptable because Aulia herself is very easily bored. The plan is to call a private teacher at home to help learn skills that cannot yet be done, considering the economic conditions are not sufficient for daily needs.

The assistance that has been received has only come from non-profit organizations , such as Gusdurian, FOI, Individuals, the Disability Group in Sidoarum Village, or from neighbors. Meanwhile, assistance from the government has not been touched at all. There are many obstacles in receiving aid, such as where his current domicile does not match the records that he has, while the conditions for getting help are residents of the local area who are indicated by their civil records numbers. There

We ended the interview with a message from Mrs. Aulia to parents who have children with disabilities to remain patient in undergoing what is given, that we are all receiving what surely is the best, because the best the plan belongs to God the giver. Consider people with disabilities as normal humans, which only distinguishes their physical condition. So be friends with them and you will learn a lot from the and keep your spirit high.

Lutfi, A Child with disabilities who being an artist

At the foot of Mount Merapi there is a village closest to the mountain. Our journey stopped in the hamlet of Kemiren, Srumbung, Magelang. A family who has a child with a CP disability named Lutfi Ramadhani, the daughter of Mr. Triyanto who was born on August 16, 2004 in Magelang. The local community knows him as one of the owners of the sand mining fleet, which also owns a business in the form of a grocery shop with his parents. He has long worked as a provider of necessities for BPNT (Non-Cash Food Assistance) recipients in the village.

Lutfi Ramadhani has a CP (Cerebral Palsy) disability because since she was born she was exposed to the CNV virus. At first, her parents did not understand the problem, but after the age of 2 (two) years, Lutfi was small, his growth and development was not like that of a regular baby her age. Then in trying to do the medical examination, the presence of a virus was demonstrated that had an impact on motor barrier. As a family that is economically capable, the parents do routine therapy, for the sake of healing their daughter by using BPJS Mandiri. Therapy is carried out in massage parlors that are recommended by neighbors or acquaintances or to clinics and hospitals. However, the progress that has been obtained is very little, so that the parents gave up and patiently accepted the fact that their daughter would be unable to walk. There was trauma for her mother, especially the fear of giving Lutfi a younger brother, for fear of experiencing the same thing. But those fears were gradually relieved by the great support from families and communities. On the other hand, they try to raise little Lutfi as a figure who is not ashamed of her limitations.

At the time of the eruption of Merapi in 2010, all residents in the slopes of Merapi from various villages took refuge in places that had been provided by the government. Barriers began to emerge while there were special needs for persons with disabilities who at that time had not been accommodated, including interrupted therapy. Until finally Lutfi's parents initiated by creating a family group with children with various disabilities. At first it was only an arisan group but the meeting became effective, when later problems were encountered by members in terms of parenting, self-confidence, difficulty in therapy and also trying to find solutions. So then there is a joint effort to accommodate therapy activities with group members to a mental hospital in Magelang.

Lutfi grew up as a confident child. Acceptance of a large family of the limitations that exist, the friendliness of people and lack of distinction, making her grow up just like any other village child. Playing and telling stories together even though the activity is carried out in a wheelchair. Her penchant for drawing and coloring was evident when she started studying at the madrasah Ibtidaiyah. Formal schools that receive Lutfi as one of the students in the learning never discriminated, because all elements support the school and help in times of trouble. There are no obstacles when socializing well with teachers and friends, and often the house becomes a gathering place to play games together online.

As parents who do not really understand technology, Lutfi's parents cannot explain what games or YouTube are. It's just that they limits her hours of using her cellphone and tells her not to see inappropriate content. However, monitoring cannot be done directly, moreover they also have to work either to deliver goods or to go to the fields. The independence that was applied to Lutfi was successful , because she could be left behind. Only when bathing, going to the toilet and wearing clothes she needs assistance. Emotional assistance can not be fully provided by the parents. It has been demonstrated that Lutfi, who also watches TV during the day, will often get upset if there is something that feels disappointing.

The assistance that had been received during the Covid 19 pandemic from BST and APBD. There was no other assistance that this family had received. However, the pandemic had less impact for the family, both socially and economically. Their place of residence which is very far from the city center makes them independent of the products produced by the city people. Their habit of eating from what they plant and planting what they eat makes them more survive in the pandemic. Changes only in the way children learn from face to face now can only be done once a week every Friday, the rest is done by way of PJJ (Distance Learning) which is not done fully online. This means that the assignment is given via Whats APP and the results will be sent to the school. The hard peers are actually how to assist Lutfi on the impact of technology, what can be accessed and what is not, and provide an understanding of sexual education. This one's a little tough if the parents are doing it.

The role of the support groups created after the eruption, during this pandemic, has become large. The change in the form of the family group with disabilities, which at that time was formed by Lutfi's father, turned into the Cerebral Palsy Children Family Association (PKACP) with as many as 70 members to this day. Becoming a big supporter starts with a routine therapy program together. By utilizing the potential of its members who own cars for transportation only by providing subsidized gasoline. Then granting independence training and teaching skills by the members of it 's own, thus minimizing operational costs. Advocacy has also been carried out to obtain health insurance and therapy as well as success by making the association as LKS (Social Welfare Institution) under the Ministry of Social Affairs so that there are several government programs that can be synergized for persons with disabilities. Selection of the right mentoring where perspective and reinforcement is done for the parents first and then the child will automatically follow and be carried away.

One lesson learned from this interview process is that when the family is able to accept the condition of their child, and does not feel ashamed and perceives it as a burden, they will try to provide the best for their child. There is also a desire to empower other families with members with disabilities. The role of groups can be felt during a pandemic like this, however problems can be resolved when there is togetherness and struggle. **(Krisna3)**