

PROCEEDINGS

APTIK International Conference

**"ENVIRONMENT AND POVERTY ON HUMAN SENSITIVITY:
JUSTICE, SOLIDARITY, AND OPEN VISION"**

The lockdown due to COVID-19 seems to be over, and now a "new vision" of life must be prepared to face our future. We believe that COVID-19 is just a disturbing phenomenon, but it does not stop APTIK's willingness to place human dignity amidst the negative disturbances to the environment and good efforts to eradicate poverty. What we need then is sensitivity to justice, solidarity and openness of vision.

This means that an open vision is the ideal method or approach to create a better world for everyone, and in accordance with APTIK's concerns, this new vision must be developed simultaneously with the world's struggle to overcome environmental violence and poverty. The novelty of this vision stands out because the difficulties caused by COVID-19 have succeeded in hitting all aspects of human life, including the perspective of a shared vision in the struggle against injustice and anti-solidarity. This may involve technological advances, health choices, legal breakthroughs, behavioral policies, and other changes.

As an organization that carries the spirit of Christianity, especially among its members, APTIK aims to provide them with the opportunity to share this spirit in and through the same flame. Moreover, because we are disturbed by the issue of "environment and poverty", this proceedings book was published to convey ideas and suggestions and take part in solving problems in building a better world for everyone to live in.



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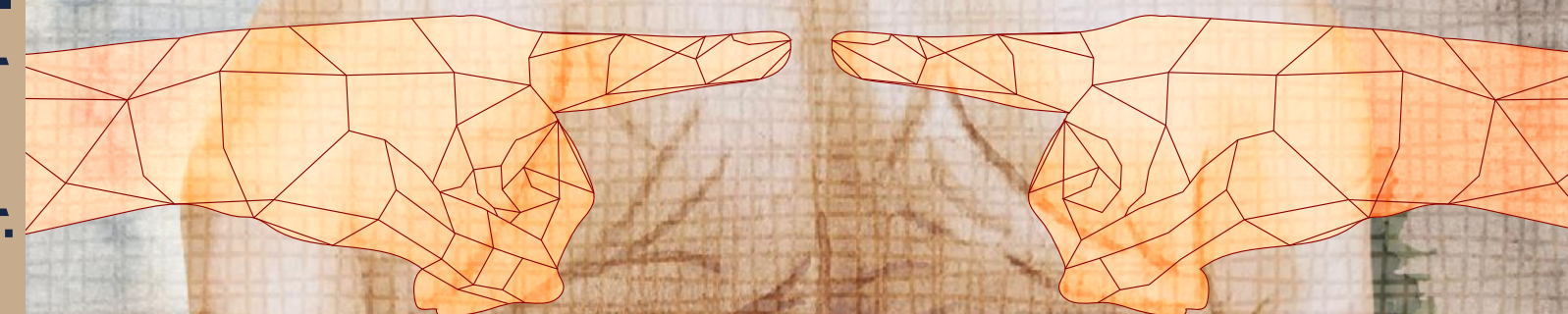
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ENVIRONMENT AND POVERTY ON HUMAN SENSITIVITY: JUSTICE, SOLIDARITY, AND OPEN VISION

8-9 September 2023
Universitas Sanata Dharma
Yogyakarta

Proceedings APTIK International Conference "Environment and Poverty On Human Sensitivity: Justice, Solidarity, and Open Vision"



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**“Environment and Poverty
On Human Sensitivity: Justice, Solidarity,
and Open Vision”**

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PREFACE

The COVID-19 lockdown appears to end, and now the “new vision” of living must be prepared in order to face our future. Indeed, the COVID-19 was just one out of the bulk of crisis torturing us, however it has already forced and pushed almost all parts of this Earth into a totally “new experience.” All activities had to break to stay alive for lockdown. They have had to wait and see what the next to undergo is. Even, some may signify that’s about the time for us to be silent and muse of our previously bad conducts. In 2020 (“A Sustainable Recovery for People and the Environment”), is still the fruitful flame for contributing the establishment of a better world for all. It means the show must go on. Our certainty is that the COVID-19, therefore, is just a phenomenon disturbing, but not stopping, APTIK’s will to position human dignity among the evil disruptions towards environment and the good efforts of minimizing poverty. What we need then is about sensitivity on justice, solidarity, and open vision.

Father General Arturo Sosa, SJ, as cited by Pedro Walpole, strongly emphasized that injustice is still the greater virus (<https://www.ecojesuit.com/learnings-from-a-crisis-in-the-time-of-covid-19>). The destructions of environment and ignorant deeds about poverty have been the phenomena, culturally and not naturally, and the struggles of overcoming them are obviously compulsory. The more powerful individual/s and groups must absolutely understand that those have been caused by the exercises of uncontrolled injustice. “This sister now cries out to us because of the harm we have inflicted on her by our irresponsible use and abuse of the goods with which God has endowed her.” (Laudato Si, https://www.vatican.va/content/francesco/en/encyclicals/documents/papafrancesco_20150524_enciclica-laudato-si.html). Lack of solidarity is also the painful destiny occurring in this present civilization, called the most advanced modern world. In order to mitigate the worst, the need of community solidarity is prominent, by the myth that everyone is kin (Kotakk, 2015, 198). However, since our civilization is continuing to undergo changes, it is a great hope that they would be in the context of improving human quality and dignity, and the emphasis on the importance of justice and solidarity is the priority. It means open vision is the ideal method or approach how to establish a better world for all, and in accordance with APTIK’s concern, the new vision must be structured together with the World’s struggles to overcome environmental violences and poverty. The newness of vision is prominent since the last hardships given by the COVID-19 have successfully struck any aspects of human life, including the common vision’s perspectives dealing with the fights against injustice and anti-solidarity. It may involve technological advancements, health options, law breakthroughs, behavioural discretions, and any other conversions.

Indonesia, who was successful in standing as the presidency of G20 last year, at present is aiming at the new national capital, called IKN, in East Kalimantan. Interestingly, the first principle, out of 8, in building it is about “the agreement with nature,” as delivered “Designed according to Nature”(<https://www.ikn.go.id/en>). The government really understands that the position of nature, i.e. environment, is prominent and ultimate to support the future Indonesian livings, and consequently nature stands as the first element to consider. This idea seems to counter the present condition of Jakarta, having complicated hardships dealing with, especially, environment or nature.

Therefore, how to improve and sharpen human sensitivity is the important question or problem for those interested in the better World. Any notions, suggestions, concepts, and contributions to create, or at least to imagine, it are waited. Our vocation of being the participants to save our Earth will be concrete later in the APTIK International Conference, hosted by Universitas Sanata Dharma, in September 2023 in Yogyakarta.

Thank you

Dr. Gabriel Fajar Sasmita Aji
Person in Charge

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SENSITIVITY AND OPENNESS IN OVERCOMING THE BURDENS OF FAMILY WITH DISABLED CHILDREN

Ilsa Haruti Suryandari
Agustinus Tri Kristanto

agustrikristanto@usd.ac.id
Sanata Dharma University, Indonesia

Abstract

This study aims to explore the role of sensitivity and openness in overcoming the burdens of a family with disabled children. Families with disabled children face bigger challenges than the typical family. For a common family, it takes a village to raise a child; however, for a family with disabled members, it needs a country since disability is closely related to poverty. This research tries to explore the perspectives of family members of disabled students at SLBN 2 Gunung Kidul Yogyakarta. While Gunung Kidul has around 6000 disabled people, there are not many supporting facilities around.

This is qualitative research. Data were collected through interviews. Interviews were conducted with families of children with various disabilities that were physical, intellectual, and sensory. Data were analysed by identifying experience, challenges and potential factors related to disability costs for the family with disabled children.

The results showed that the hardest challenge among parents with disabled children comes from the environment surrounding them. It reveals that sensitivity, specifically disability sensitivity that involves empathy and emotional responsiveness, plays an important role in promoting a healthy environment for the growth of disabled children. Furthermore, sensitivity, also closely related to openness, consisting of effective communication, mutual support, and willingness to seek external resources, is another key factor in overcoming the burdens associated with raising disabled children. In the future, this disability sensitivity and openness will be supported and integrated into government policy in the poverty alleviation programme.

Keywords: Disability; Human Sensitivity, Justice, Openness, Financial Burdens

Introduction

Poverty and disability have been closely related. Disability is part of the vicious cycle of poverty (Palmer, 2011). In some rural areas of the world, the increase of disability is consistent with the increase of poverty (Kheir, 2023). This issue has also become a serious concern in low-middle-income countries (Banks et al., 2017; Kusumastuti et al., 2014). Thus, it becomes the main concern for several organisations that resulted in the establishment of some movements such as the Universal Apostolic Preferences of the Jesuit, Laudato Si, and Sustainable Development Goals.

Disability have strong impact on poverty due to the burdens following the handicaps. This challenge is called disability cost. There are several studies on disability costs, ranging from low-middle-income countries (Asuman et al., 2021; Mont et al., 2022; Palmer et al., 2015, 2019; Raut et al., 2014; Van Minh et al., 2015) to the upper income countries (Arora et al., 2020; Doran et al., 2012; Hirsch & Hill, 2016; Knapp et al., 2009).

Disabled people not only overcoming the additional cost related to their impairment. They also experience discrimination that may hinder them in fulfilling their needs. It is

common to see an employment gap between the disabled and typical employee (Geiger et al., 2017). Moreover, some disabled people also experience some hindrance to participating in decision making (Lotan & Ells, 2010). This will be more severe when women suffer from disabilities; they need to struggle harder than their male peers (Astutik, 2019).

Although disabled adults face some challenges in their life, disabled children affect not only their own life but also their family members. Families with special needs children experience psychological (Djap et al., 2021; Khairunnisa & Hartini, 2022; Ricou, 2020)(Djap et al., 2021; Ricou, 2020) and physical (Bixby, 2023).

It takes a village to raise children, but a country needs to raise disabled children. Families of special-need children cannot survive alone. They need support systems consisting of many elements such as extended family, community and country (Chawa et al., 2021; McCormick et al., 2021; Ratti et al., 2016; Verdugo et al., 2020; Wardany et al., 2018). Therefore the families with disabled children can ease the burden.

Sometimes, the support provided is not in accordance with the needs of the family. This is due to the variety of disabilities. Thus, a combination of internal and external factors is required. The openness of the family as an internal factor can help others understand what they need (Boström & Broberg, 2014). Additionally, sensitivity is necessary for external parties to help them understand the intention of the family (Jazukiewicz, 2020).

This research tries to explore the role of sensitivity and openness in overcoming the burdens of family with disabled children. This research also tries to answer questions about the needs of families with special needs children, their challenges, and how sensitivity and openness help them overcome those challenges.

Methodology

This is a qualitative descriptive approach. This research is intended to gain a deeper understanding of the perspectives of families with disabled children on disability cost, while also investigating the existence or importance of sensitivity and openness in this matter.

Data were collected by interview. Interviews were conducted to explore the perspectives and experience of family members. Respondents to this research are family members of the disabled student at Sekolah Luar Biasa Negeri (SLBN) 2 Gunung Kidul Yogyakarta. SLBN 2 Gunung Kidul is a special school in Gunung Kidul regency. Gunung Kidul regency has around 6000 disabled citizens. SLBN 2 Gunung Kidul is also one of the few special schools that provides a dormitory for students located near the school area.

There were several steps in analysing the data. First, the interview data were analysed to understand the perspective of the disabled child family about their challenge in raising special needs children. Although challenge could also be considered a burden, this research tried to explore the met and unmet need of families with children with special needs.

Second, data were analysed to search for sensitivity and openness issues in the effort of a family with disabled children. Therefore, this research investigates the role of sensitivity and openness in helping the family of special needs children.

Results and Discussions

Experience of Special Needs Children's Caregivers

Most parents and caregivers of disabled children at SLBN 2 Gunung Kidul have a low educational level and will have difficulty participating in research. Therefore, this investigation involved only three family members who agreed to participate in this investigation.

One of the participants is Mr. A. He is the father of a high school junior with intellectual disability. The participant works in the informal sectors. The other two participants are housewives. The first woman, Mrs. N is the mother of a third-grade elementary student with hearing and physical impairment. The other woman, Ms. S, is the sister of a third-grade elementary student with severe non-verbal autism spectrum disorder or sensory disability. She became the caregiver for the child because their parents passed away last year.

Mr. A's son was diagnosed with intellectual disability when he was in kindergarten. However, Mr. A regretted that only after almost three years of kindergarten, the teacher told him to bring his son for a doctor checkup. He used National Health Security, known as BPJS Kesehatan, to fund the diagnosed fee. He wished he knew earlier that his son had special needs.

Mr. A's son previously has discrimination and was bullied by the neighbors. However, the late head of the special school gives Mr. A motivation. The headmaster told Mr. A that the Special School is neither a hospital nor a witch doctor. This school is like a workshop that has a very broad opportunity. Therefore, they cannot expect special-need children to become exactly like typical children. The school objectives were to help minimize their disability so that they can live a decent life like typical children. Later, Mr. A became very active at every society meeting to educate the neighborhood about his son's condition.

Mrs. N has a different experience than Mr. A. Her son was born as a normal baby. Only after he reached around four to six months did he develop a disease. This condition left him with hearing and physical impairment. The physical impairment made him unable to walk normally. Ms. S has just taken care of her sister since their parents passed away. Her husband became the sole breadwinner in the family since Ms. S has to be a stay-at-home mom to take care of her daughter and sister. Ms. S's sister only receives intervention during school time. Until now, she has not received any additional medication or therapy.

Disability costs

People with disabilities have a barrier to obtaining a standard of life similar to that of normal people. The disability can prevent them from performing some activities that are common for typical people. Therefore, to obtain a similar standard of living, disabled people have to spend more than typical people to pay the additional cost due to disability (Asuman et al., 2021; Mitra et al., 2017; Mont et al., 2022; Palmer et al., 2019; Schuelke et al., 2022). Furthermore, the burdens also have impact not only on the disabled person, but also on family members.

The cost of disability is closely related to the type of disability. The three children in the families of the participants have different needs. This research divides the cost of disability by tangible cost and intangible cost.

Tangible costs are related to direct and indirect costs that can be physically measured by monetary value. On the other hand, intangible costs are related to costs that cannot be directly measured by monetary value (Razzouk, 2017).

The medical cost is the most common tangible cost for special needs children. Most disabled children need medication for their entire life. Some intellectual disability is often followed by several other health problems, the most common being epilepsy and gastrointestinal disturbance (Kerr et al., 2003; Sappok et al., 2019). Although autism spectrum disorder (ASD) is also sometimes related to intellectual disability, some type of ASD, especially with hyperactive and attention deficit problems, needs routine medication to help them calm down and focus (Levy & Hyman, 2008; Trudeau et al., 2019). For the type of physical disability, the medical cost is closer to the purchase of aid. Hearing impairment also needs assistive technology. Meanwhile, autism spectrum disorder (ASD) requires various kinds of therapies. The most common therapies for ASD are behavioural therapy, speech therapy, sensory integration therapy, and occupational therapy (Domínguez-Lucio et al., 2023; Georén et al., 2022; Randell et al., 2022; Sabzevari et al., 2023). The cost of disability as a result of the high cost of medical treatments, therapies, specialised equipment, and assistive technology can cause financial hardship for families.

Fortunately, in this research, Mr. A's son does not have any additional health complications. He mentioned that the school previously provided a routine medical check-up consisting of physical and psychological examination. However, the facilities have not been continued in the last two years. *“There was regular health monitoring, especially from first to fourth grade. Internal, external health, and even psychology were there. But now,*

perhaps due to school finances or government assistance to schools, this activity has been interrupted for the past 2 years or so."

Ms. However, N's son needs more medical treatment. Treatment ranges from consultation with a pediatrician, therapy, and assistance. *"Speech therapy and physical therapy, as well as doctor consultations"*

Mrs. N's son received treatment since he was 10 months old. She took him to the hospital with National Health Security. Mrs. N also regularly took his son to the pediatrician. He received some therapy, such as physical therapy and speech therapy. Some of the therapy was provided by the school, and the other was provided by the parents. Later, due to the financial problems of the parents, the therapy was stopped. *"I used to go to Sardjito (Hospital) two to three times a week with BPJS. There are no costs for going to the hospital, just going to the doctor. I used to do therapy myself. But now we cannot afford it, so we only rely on school facilities."*

Due to hearing and physical impairment, the doctor suggested the use of a medical aid. However, due to economic problems, the student stopped using assistive technologies. *"I bought a hearing aid, but only used it for 1 year. I used to go with my husband to Jogja, but he returned home and we did not continue with it. Buying the battery is 60 thousand a month, there is no money to commute."*

Children with disabilities cannot join ordinary educational institutions. This is related to the experience of the participants. *"In the past, he went to regular kindergarten. He could not do anything there."*

Consequently, children should join special educational programmes. Since special educational programmes are usually customised as an individual educational plan, the programmes require higher costs than regular educational programmes. Special-need children can also join inclusive programmes (Jauhari, 2017; Mayasari, 2016). Fortunately, they can access the special school provided by the government without paying a tuition fee. *"It's free. I only provided fuel for transportation, plus intention and a healthy body. Just that."*

Disabled children also need special care. This may force family members who act as caregivers to work fewer hours or to give up the jobs entirely. This situation may also further worsen the financial stability of the family. This situation occurs to Ms. S as the caregiver for her sister. *"Since our parents passed away, I don't go to work because I have to take care of my sister."*

The family can incur unexpected costs as a result of their child's handicap. The unexpected costs are related to home adaptations, travel expenses, or legal fees associated with obtaining disability-related benefits. *"Our home is far away. Its hard to escort him since he also has a younger brother who goes to regular school. "*

The psychological burdens of a family with disabled children may not be easy to recognise. This can be included as intangible costs. Special-need children bring more uncertainty and unpredictability; therefore, increase the emotional stress of caregivers. They may experience a higher level of anxiety and depression as a result of their ongoing concern for the welfare of children. *"I want, for example, if I am no longer there, my child's mother is not there, my child can be independent."* This also resulted from stigma and pressure from the environment.

"If we look into the past..... (unable to speak), if people here say 'peyung-peyung' (that means stupid) like that, it hurts here, ma'am, (pointing to chest)."

"Small children who are still in kindergarten don't know about autism, calling her crazy"

Additionally, due to the difficulties of caring for a disabled child, it may result in social isolation.

"In the neighbourhood, she seems invisible. People stay away because they think she is crazy. I am alone, I don't have anyone to help me even from the family"

Fulfilled Needs

Indonesia provides Special Needs Schools in all regions. Therefore, children can have basic educational needs. Moreover, the special school does not also charge tuition fees for students. Indonesia has a social security system called BPJS (*Badan Penyelenggaraan Jaminan Sosial*). The national health service in Indonesia is called BPJS Kesehatan. BPJS Kesehatan provides their basic health needs that can help them access diagnosis of disability, medical check-up, paediatrician consultation, and therapy.

Unfilled Needs

There are still some unfilled needs due to various reasons, such as the limited knowledge, that make them unable to get earliest disability detection, as stated by Mr. A and Ms. S.

“What I regret was that the kindergarten teacher said that he had special needs, but it was already approaching 3 years in the kindergarten. Well, that is what I regret. Finally, one of the kindergarten teachers said: “Sir, your son has special needs.” At that time, I had BPJS (National Health Systems), then I consulted with the hospital.”

“In the past, my parents had no knowledge. My sister was born prematurely. But at normal age, when she should be able to walk, she could not walk yet. So she just got a traditional massage.”

Both the sons of Mr. A and Ms. S’s sister got a formal diagnosis after they reached school age, and that was due to the fact that they could not follow the regular educational curriculum. Mrs. N has a different experience. Since her husband works in the city, she got better information. Furthermore, the disability of her son was caused by certain diseases. *“He was born as normal children. But when he was around four to six months old. He got sick like a chicken pox. That’s where everything started.”*

As a child with ASD, Ms. S’s sister should receive various interventions. National Health Systems also provides facilities for ASD therapies at general hospitals in Yogyakarta. The special region of Yogyakarta also has an Autism Centre in Kulon Progo. However, the facilities are far from Gunung Kidul. Therefore, her sister does not receive the sufficient intervention needed. *“She does not take any medicine. She also does not have therapy. She just goes to school.”*

Sensitivity

Sensitivity is an important factor when interacting with disability. Due to diversity of disabilities, each special needs individual cannot be treated as similar individuals. This is particularly important for entities that deal with disabled people. This applies to professionals who will work with disabled people and government who will accommodate the special needs citizen (Peterson & Quarstein, 2001). Often, government policies work partially. It only accommodates part of the community, while actually it can also be utilised by other target groups.

“During the rainy season, he wants to raise catfish. He is happy, so I just let him be. That kind of children are mostly in the agricultural sector, right? Here also on an agricultural basis. Unfortunately, government or non-governmental aid is intended for farmers who work in the paddy field. For the kind of livestock, our children also need some kind of help. Farmer groups do not accommodate special needs members. Actually, they can, they just don’t understand. The environment determines the future of children.”

From that sentence, we found that people do not understand about special needs people. In this way, they need to employ empathetic understanding. It is a form of simulation that is also an epistemic means of understanding other people's minds (Hannon, 2020). With some understanding, we can help them according to their needs. *"It happened that I met Ms. Through an acquaintance, she supported my decision to register my son in special schools. In special schools, I met the late headmaster. So yeah, I am currently very enthusiastic."*

From the sentences above, the caregiver got an emotional response from the teacher. It is a kind of support that can help them reduce the psychological burden and provide more motivation. Emotional responsiveness helps to resolve root problems and acknowledge negative emotion (Byun & Jeon, 2023).

Openness

The caregivers in this research show that openness helped them ease their burden in raising disabled children. Communication openness build trust between parties in a relationship to reflect the degree of information sharing (Boström & Broberg, 2014; Conley & Nadler, 2022; Martínez-Tur et al., 2020) *"But now, when I go to community meeting , I tell them that basically my son is like this. My son has special needs. I beg them that if my son is rude, remind him and do not discriminate him. However, do not use violence, or you will have trouble with your father. "*

Part of the openness is the support from several parties, also helping the family with disabled members. This will make them feel accepted and at ease. *"Alhamdulillah, there are not many problems with the family. The children in the neighbourhood also understand that my son cannot hear and cannot talk. Many people care and his friends can understand his situation."*

From an internal point of view. The openness of family members can also help them to have a willingness to seek external resources. This will reduce their workload. *"I asked his older brother to help this kid, for example, who wants to open Youtube. Since then, there has been no distance between his communication with his friends. There is no longer any distance. If he doesn't know, he can ask the teacher."*

Conclusions

The disability costs of family members with special needs children are related to physical and emotional factors. However, not all needs can be met independently by families. Therefore, the support of the surrounding environment, especially from extended families, the neighbourhood and the government, plays an important role for families.

To help families with members of special needs, it is important to involve sensitivity in the process. Sensitivity as an external factor to support families. Sensitivity in this case is related to empathetic understanding and emotional responsiveness.

Meanwhile, family members of disabled children should also embrace openness. The openness in this case is effective communication and mutual resources that require the cooperation of internal and external factors. However, family members should also have the willingness to seek external resources, so that people know how to help them.

This research has some limitations. The first limitation is related to the type of disability. In this research, we only discuss hearing and physical impairment, intellectual disability, and autism spectrum disorder. Second, this study has not added a monetary proxy for the cost of disability, nor the impact of sensitivity and openness on the family with members of special needs. Thus, future research is expected to add different types of disability and explore the monetary impact of sensitivity and openness. There is also an opportunity to explore the integration of sensitivity and openness into the government's poverty alleviation programme for disabled people.

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