The Resilience of Families with Cerebral Palsy Children: Implications for Social Protection

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ABSTRACT

There are generally agreed by both professional workers and laymen that the resilience of families is influenced by emotional climate of the family. This study aims to provide an overview of resilience in families with children who have cerebral palsy, who attend YPAC (Foundation for Disabled Children), which is the only centre for cerebral palsy services in Jakarta. Qualitative research was used to analyse a case study featuring three (3) separate families, with each family having two (2) children with cerebral palsy. The result of this study describes the Family Resilience by looking at risk factors and protective factors in families with Cerebral Palsy children and all their limitations. Risk factor is the condition of the informant, who has insufficient and unstable income. On the other hand, family members also receive discrimination regularly, and even experienced physical violence. Meanwhile, protective factor is a source of strength from their personality or values of each member of the family, commitment, and support from the surrounding environments, such as extended family, friendship groups, neighbours, and institutions. Social support becomes a source of strength for the family and keeps their fight with their children with cerebral palsy. Apart from internal factors, their relation to their environment also supports the family's resilience.

Introduction

People with disabilities become one of the issues that need attention. Based on Susenas data in 2018 there are 14.2 percent of the Indonesian population with disabilities or 30.38 million people (Anshori, 2020). According to the data from Central Bureau of Statistic in Health Ministry of Indonesia (2014), the percentage of people with disabilities in Indonesia continues to change, where the percentage increased in 2012 to 2.45%. However, according to the Indonesian Ministry of Health (2014) and research conducted by Witterberg and Sa'ada (2013), cerebral palsy is categorized as a type of severe disability. Cerebral palsy can be a particular burden in childhood for the sufferer and has a significant impact on the person's family (Valentina, 2014). People with cerebral palsy are paralyzed from birth or during the first five years of their lives. It can be an obstacle to the child's motor development (Bower, 2009) and can also trigger difficulty in controlling the muscles as a result of paralysis or damage to the brain (Slaich, 2009).

Children with disabilities have the same rights with other children around the world (UNICEF, 2013). Based on Law No. 23 of 2002 concerning Child Protection, it is stated that every child has the right to live, grow, develop, and participate fairly and get protection from violence and discrimination. Regulation by the Minister of Women's Empowerment and Child Protection of the Republic of Indonesia No. 4 of 2017 concerning special protection for children with disabilities stated Special Protection for Children with Disabilities is a form of protection received by children with disabilities to fulfil their rights and get a sense of security, against threats that endanger themselves and their lives in their growth and development. As well as children with disabilities have the right to be free from discrimination and obtain facilities and get access to social services.

The birth of children with cerebral palsy has an impact on their family in terms of their health, social and economic well-being (Wittenberg and Saada, 2013). Parents must do twenty hours parenting patterns and cover high costs to meet the needs of children with CP. Families and those closest to the children with CP play a significant role in stimulating the children's development and teaching the children to explore new things, such as how to eat, talk, walk, and interact socially (Braga and Paz, 2006).

Some studies related to people with disabilities including research conducted by Suharli (2000), stated that family is the key to Children with CP Rehabilitation Process. Research on disabled children by Melani (2014) about Evaluating Occupational Therapy Programs shows that children who are physically disabled, with the majority of whom are people with CP, must undergo therapy for the rest of their lives. While research related to family resilience from Apostelina (2012) on Family Resilience in Families with Autistic Children shows the importance of the role of their family and extended family. Research from Satriyo and Yumpi (2017) illustrates the low ability of families who have children with Disintegrative Disorders in regulating emotions causing crises that include frustration, anxiety, shock, helplessness, anger, sadness, and resentment.

The studies above show the problems faced by families who have children with disabilities or special needs which focus on the families' resilience. However, they do not show how the environmental dimension supports family resilience. A study conducted by Walsh (2016) states that each individual has the potential to build resilience. The study explains that resilience can be gained through experiences in facing difficulties. The individual will build an internal strength while waiting for help from others (external), in other words resilience is a result of life experience.

Families who can adapt and carry out their functions in the midst of the problems face dare called families that have buoyancy or resilience (McCubbin, 1997 in Mawarpury and Mirza, 2017). Family resilience is the ability of a family as a functional system to survive and recover as in its original condition when facing difficult conditions (Walsh, 2016.) According to Patterson (2002), a family with disabled members will be considered resilient if they can fulfil the family member's vulnerable protective function. The outcome of the function is family capability in providing care for children with special needs, making sure that there is no violence in the family, and avoid sending their children to care institutions.

The most significant issue is how children with CP obtain therapy and care for their entire lives. Children with CP's need of assistance and extra necessities in carrying out daily activities cause stress to the family (Valentina, 2014). Some families with children with CP hire caregivers to help their children's mobilization. However, not all families with children with CP can hire caregivers. Families who cannot afford to pay for caregivers must take care of their own children. The burden experienced by the family will be multiplied when the family has more than one child with CP. In addition, there is a lack of understanding and support from their neighbourhood environment on disability issues, causing family members to experience stigma and becoming victims of verbal violence. The objective of this research is to understand the resilience of the families who have children with cerebral palsy and successfully take care of their children without the help of caregivers.

Cerebral Palsy Children in Literature Perspective

Cerebral palsy is a brain paralysis condition which results in inhibition of individual motor development (Bower, 2009). Every child who has cerebral palsy has different conditions, from mild to

severe. Brain damage suffered by people with CP can cause other obstacles, such as mental retardation, epilepsy, visual or hearing impairment, communication difficulties, and eating difficulties (Hinchcliffe, 2007; Bower, 2009). Undermined body functions in people with CP can worsen with age and they might miss several stages of child development (Slaich, 2009).

Resilience can be defined as the ability to survive and recover after facing life difficulties (Walsh, 2016). Resilience is a dynamic process that develops an individual's adaptability when encountering adversity. Resilience is not just the ability to overcome and adjust to adversity, but the strength and resources that enables individuals to recover from a setback and continue their lives (Walsh, 2016).

Various definitions of resilience from previous studies emphasize the process of positive adaptation supported by the ability to rise from bad and painful experiences (Smith-Osborn, 2007; Bonano, 2004; Richardson, 2002; Luthar, Cichetti, & Becker, 2000). Resilience is a concept that was originally developed in the context of developmental psychopathology and is based on an ecological, stress and coping perspective (Smith-Osborn, 2007).

Stressors are a part of human existence and successful coping is important for health. The study of stress in families carried with the assumptions that: 1) family members interact and support each other, 2) the presence of stressors requires the family to be able to adapt and make adjustments and, 3) certain rules and communities will encourage family coping and adaptation (McCubbin & MCubbin in Nichols, 2013This perspective contributed to social functioning in the family where family has the ability to improve itself. Family resilience is a combination of individual characteristics, patterns of relationships, and interactions between members in the family so that resilience is formed from strong and positive relationships in the family. (Patterson, 2002; Walsh, 2006; Greef & Human, 2013).

Family resilience is rooted in a positive perspective and sees the family as a collective unit of a number of individuals who interact and have their own strengths. Family resilience develops when a family is considered as a functional unit which encourages the family members to be resilient (Walsh, 2003).

McCubin (1997) mentions two components of family resilience, namely a) the family's ability to maintain a functioning pattern that is developed after adversity and pressure; b) the ability of the family to recover quickly from trauma or stressful events that cause changes in the family. These two components in family resilience are referred to as elastic characteristics and buoyancy.

Mackay (2003) states that the key concept of family resilience comes from three factors, namely protective factors, risk factors, and vulnerability factors. Meanwhile, McCubbin, McCubbin, Thomson, Han, & Alley (1997) identified that family resilience factors consist of protective factors, recovery factors, and general family resilience factors.

Family protective factors include family celebrations, family time and routines, and family traditions. Recovery factors include family integration, family support and self-esteem building, family recreation orientation and family optimism. Meanwhile, general family resilience factors may act as protective factors and family recovery factors which include problem solving strategies, effective communication processes, equality, spirituality, flexibility, truth, hope, social support, as well as physical and emotional wellbeing. The descriptions above give an overview of the main factors that can build family resilience and these factors can be divided into two, namely: a) internal factors (factors that come from the individual, including cognitive capacity, communication, emotion, flexibility , spiritual), and b) external factors (factors that come from outside of the individual, including support from other family members,

spending time with family, good financial condition, and good relationships with the social environment. (McCubbin, McCubbin, Thomson, Han, & Alley (1997).

According to Walsh there are two factors in looking at resilience: risk factors and protective factors. Risk factors are predictors or signs that make individuals vulnerable to the problems in the future (Kaplan, 1999 in Kalil, 2013). Risk factors can occur at the level of individuals, families, communities, and even the wider community. Risk factors consist of potential obstacles, threats, or unfavorable situations that can prevent the family from functioning optimally (Bhana & Bacoo, in Cripe, 2013). Several risk factors that have been studied previously are job loss, poverty, divorce, death, chronic disease, and infertility (Kalil, 2013). Although risk factors is a threat to resilience, individuals with the same risk factors may have different resistance level.

Vulnerability is a condition that makes families more susceptible to the adverse effects of a crisis. A family is considered a vulnerable family if they experience the following conditions: (1) insufficient and unstable economic income, where the family lives below the poverty line and is homeless; (2) no access to health and educational facilities; (3) not getting social support from their environment and help from other family members, neighbors, or relatives; (4) being stigmatized, a victim of stereotypes, belittled, treated unfairly by those around them because they are considered different; (5) have an ill or disabled family member; (6) have been a victim of physical or verbal abuse (Myranska, 2013).

Protective factors are factors that can strengthen a person's resilience (Walsh, 2016). Protective factors minimize the impact of the problems that occur to a person (Kalil, 2013). Protective factors give strengths to the families to overcome various existing obstacles and to function optimally (Bhana & Bacoo, in Cripe, 2013). Protective

factors come in the form of a perspective on the environment, affection in the family, family support, and children's support (Kalil, 2013).

Furthermore, individuals with an external control center think that they have no role in changing their fate and are easily influenced by the environment. Whereas according to Juby and Rycraft (2004), individuals with an internal control center believe that they: can control their fate; can change their situations; and can create the situations they want (Benzies and Mychasiuk, 2009). Individual with internal control centers is not easily affected by crises.

According to Stewart, social support refers to interpersonal interactions between families and their social networks, such as extended families that provide emotional support, help, or information (Stewart, 1993 in Benzies and Mychasiuk, 2009). Resilient family is a family that shows interaction as something dynamic, an integration of protective and remedial factors that include optimism, spirituality, harmony, flexibility, communication, financial management, time and recreation, routines and rituals, and social support (Patterson, 2003).

Previous resilience studies have examined individual resilience, but resilience itself can be seen in larger analytical units such as families, groups, organizations and communities (Myers & Taylor, 1998; McCubbin, 1988; Brody & Simmons, 2007; Cohen, Slonim, Finzi, & Leichtentritt, 2011).

Research Method

This research was conducted at Yayasan Penyandang Anak Cacat (YPAC), the largest educational institution, treatment, and shelter for children with cerebral palsy in Jakarta. YPAC was established over 64 years ago. This study was conducted with qualitative approach. Creswell (2014) defines qualitative approach as

a research process with a particular methodology, in order to explore and understand the meaning of individuals or groups that are related to the phenomena being studied.

In this study, researchers used a case study research to understand and interpret family resistance with children with cerebral palsy. A case study research discusses privileges in several cases of individuals, groups, organizations, movements, events, or geographical units (Neuman, 2014). One of the strengths of using case studies is that researchers can link an abstract idea into a concrete case (Neuman, 2014). As for this study, the researcher aimed to see the features of a family with cerebral palsy children by connecting the situation experienced by individuals with pressures from the surrounding environment. How families with children with CP faced their situations and how the surrounding environment responded to the existence of children with CP.

Data for this study was collected by depth interview, observation and documentation study related to the research topic. Literature study for this research was carried out by utilizing library materials, such as books, online media, journals, legislation, and official government documents. Observation is a method of monitoring a social condition. Neuman (2014) states that an observation was done by looking at the conditions and activities of families with children with cerebral palsy.

The researcher used purposive sampling to select informants. Purposive sampling is used to select informants who are difficult to reach and coming from special populations (Neuman, 2014). The informants in this study are the Head of Development Unit and teachers at YPAC and parents with children with cerebral palsy, with the following criteria: (1) have more than one child with cerebral palsy; (2) do not have a babysitter; (3) not divorced; (4) their families have a place to live and have no history of violence.

Result and Discussion

Each of the three families have two children with moderate cerebral palsy (30%), which means they have very limited activities and mobility. Their children have multiple disabilities (hearing-impaired and mentally disabled). Having a severe mental disorder making it difficult for them to communicate and causing them to experience vision impairment and limbs paralysis. That is why having children with CP takes up time and energy for parents, especially mothers because children with CP need constant assistance from the people them at all times.

Physical limitations make children with CP dependent on their parents, especially in mobilization in their daily activities. The three informants have an improper sleeping pattern because they have less than 5 hours of sleep in a day, resulting them to delay other chores and responsibilities to take care of their children with CP all day long. According to Wittenberg and Saada (2013), families who take care of children with CP experience pain in the body due to helping their children's mobilization, sleeping disorders, unable to move freely at home and having unhealthy work pattern.

During their busy time they have, the families still spent their time to take care and and tryd to meet the educational needs of children. CP children attended education at *YPAC* (Foundation for Disabled Children) Jakarta.

Walsh (2016) mentions that like all individuals, every family has different sources of difficulty and sources of strength in facing a crisis. According to Patterson (2002), the source of difficulties and sources of strength exist in all layers, such as individuals, families, and communities.

The three families experience a crisis in the form of anxiety and sadness while rising children with CP. Therefore, families need to adapt to carry out their functions in the midst of the problems at

hand (McCubbin, 1997 in Mawarpury dan Mirza, 2017). Resilience emphasizes the process of positive adaptation supported by the ability to rise from bad and painful experience (Smith-Osborn, 2007; Bonano, 2004; Richardson, 2002; Luthar, Cichetti, & Becker, 2000).

Families who can adapt and carry out their functions in the midst of the problems mentioned as families that have buoyancy or resilience (McCubbin, 1997 in Mawarpury and Mirza, 2017). Family resilience is the ability of the family as a functional system to survive and recover to its original condition when facing difficult conditions (Walsh, 2016), where family resilience can be determined through the families' sources of difficulty and strength (Patterson, 2002).

Myranska, et al. (2013) stated that a family can be categorized as a vulnerable family if the family has children with CP, has insufficient and unstable income, no access to health and educational facilities, not receiving social support from its environment, stigmatized, and a victim of violence.

Factors that can threaten resilience are called risk factors. It consists of potential obstacles, threats, or unfavorable situations that can prevent the family from functioning optimally (Bhana & Bacoo, in Cripe, 2013). The three families have economic limitations. Their irregular income has put the family in economic difficulties. However, having children with CP requires a great amount of money for the continuity of a life-long therapy. One of the informants experienced a rejection by not being permitted to access one of the hospitals because she could not pay for medical expenses. The dismissal, expensive fees, and no improvements of the child's condition make parents feel traumatized to get further medical treatment. Later on, the three families obtained services at *YPAC* (Foundation for Disabled Children) Jakarta.

Informants experience verbal and non-verbal stigma, such as being stared at. According to Myranska (2013), being stigmatized

is being victimized by stereotypes, lowered self-esteem, and unfairly treated by people around them because they are considered different. Families with Celebral Palcy children experience pity or dislike from those around them, there are even people who comment that they do not want to have children like those family. As a result, families keep their distance and even close themselves from their environment, especially from their neighbors. One of their normal child even experienced verbal bullying or violence in school due to having siblings with Celebral Palsy.

The protective factor in family resilience can be seen by how families adapt. Resilience is formed and learned through experience in dealing with misery (crisis). Every individual has different sources of difficulty and strength when facing a crisis (Walsh, 2006). The resilience of each family can change from time to time. Thus, it can be determined that family resilience is a process and not an outcome (Rutter, 1999 in Benzies and Mychasiuk, 2009).

The experience of having children with CP triggers psychological impacts to all informants, such as sadness and resentment over the condition of their children. They feel sad about the condition of their children who cannot be independent in their adulthood. They are also worried about the survival of their children if both of the parents die. However, sometimes parents are frustrated with their children's limitations in understanding something.

These parents did not take their anger on their children because they know that these limitations are not favourable by anyone. They tried to regulate and manage their emotions. According to Shaffer, et al (2005) in Benzies and Mychasiuk (2009), by having the ability to regulate and manage their emotions, family members can think calmly during stressful situations. Families focus more on how to take care of their children, than their sadness or frustrations. Cicchetti & Rogosch explain that the stress or adversity generated by various unpleasant

situations must be of a severe degree, reflecting substantial hardship and high risk to have the potential in exacerbating a prolonged crisis (Werner, 1995; Luthar, 2000; Rutter, 2005 in Marty Mawarpury, Mirza 2017).

The parents' ability to regulate their emotions becomes one of the sources of strength (protective factors) and to minimize the impact of the occurring problems. In this condition, the source of strength can help families to adapt and overcome their problems (Kalil, 2013). The source of strength can arise from the personality or values of each family member (individual), values and commitments among family members, and support from the surrounding environment, such as extended family, friendship groups, neighbours, and institutions.

Support from partners is the best support to improve the ability to overcome family economic and social problems (Van Doesum, et al, 2005 in Benzies and Mychasiuk, 2009). Husbands or wives support their partner by giving attention and cooperating in taking care of their children, especially if they do not have a caregiver.

According to Benzies and Mychasiuk (2009), a good relationship between husband and wife is characterized by good communication between the two, so that it can create a comfortable environment for children to develop. Partner support can relieve stress because spouse is the closest and best person to share their problems with.

The assistance received by the family can come from within the nuclear family and extended families. According to Benzies and Mychasiuk, (2009), extended families can give social supports, such as instrumental and emotional support, or any help to the families to deal with their problems. According to Benzies and Mychasiuk (2009), social support of extended family can also be in the form of emotional support, real help, or information. The three families in this study receive emotional support and help from their extended family to take care of the children in the hospital and take turn in taking

care of their children at home. Two of the three families in this study also receive financial assistance from their extended family.

One source of strength in family resilience is having cooperation, support, and commitment among family members to go through a shared crisis, or what according to Walsh (2016) is called family closeness. The three families in this study have good family closeness. According to Benzies and Mychasiuk (2009), family resilience is not only influenced by individual characteristics and interactions within the family but also influenced by the community and the physical environment around the family. Family involvement in the community opens up the family's opportunity to obtain information about health and educational services and increases the emotional ties between community members. In this study, the three families are not involved in the organization, but they have informal friendship groups that help them to obtain information. The friendship group is the parents' friendship group of students at YPAC. According to Criss, et al (2002) in Benzies and Mychasiuk (2009), acceptance of among the friendship groups is the strongest source of strength compared to other community social interactions. In this study the three families receive good acceptance from the parents of students at YPAC and their friendship grew closer like a family. Their children with CP are also well accepted and they can socialize around the school environment. This friendship group works together to reduce financial burden of each other's family by holding joint activities and helping to find donors to financially support the parents in need.

In addition, good access to children's education and health services is marked by the opening of opportunities for children to obtain education and health services. According to Patterson (2002), families with disabled children are considered to be resilient when they can provide care for their children with special needs, making sure that there is no violence in the family, and avoid sending their

children to care institutions. The three families in this study have good access to education and health services at *YPAC*, and receive cost subsidy and financial assistance from donors.

Jakarta Regional Government supports the people with CP who live in Jakarta Special Province by giving them the Jakarta Smart Card (KJP). With the assistance from *YPAC* (Foundation for Disabled Children) and the Regional Government of Jakarta Special Province, families with low economy can still carry out their protection functions and build family resilience.

Furthermore, the families also had a source of strength from the neighbourhood. A safe living environment includes low crime rate, a large number of infrastructure facilities, and supportive neighbours (Benzies and Mychasiuk, 2009). In this study, two out of three families have supportive neighbours who accept their children's condition and encourage each other. These friendly neighbours help one of the families in this study when they are stigmatized by other neighbours. Responses from the friendly neighbours were influenced by their relationship with the informant and how long the informant has lived in the area. Neighbouring environment and friendship can also be a source of strength.

Individual and environmental factors affect a family's process to survive various crises that occurs. Family resilience is not only supported by factors within the family but also how families relate to their environment. Available social support can help individuals to survive. Positive social support is the key to family resilience when meeting individual needs (Harms, 2010). The survival of families with children with cerebral palsy comes from the parents, extended families' support, neighbourhood environment, friendship communities and *YPAC* (Foundation for Disabled Children) institutions.

Potential pressures that arise in families with children with cerebral palsy, such as financial barriers, limited family leisure

time, disturbed marital relations, and negative social stigma can be risk factors for the families. Meanwhile, protective factors include communication between family members (Pandanwati & Suprapti, 2013), social support (Greef & van der Walt, 2010), family coherence (Maulidia, Kinanthi, Fitria, & Permata, 2018; Uswatunnisa, Brebahama, & Kinanthi, 2018).

A multidimensional approach is a holistic approach that addresses human behaviour and its development (Harms, 2010). According to Harms (2010), individuals have biopsychosocial and spiritual dimensions, which change due to individual factors (inner world) interacting and having reciprocal relationships with their environmental factors (outer world).

Both family factors and their relations to the environment affect family resilience. Environmental factors (outer world) consist of relational and social dimension. Relational dimension is a scope or setting where individuals live, work, and play (Harms, 2010). In this scope, individuals depend on their confidently and identity which in a phase, this dimension will help individuals to survive. Social dimension covers social support which becomes a significant thing in maintaining and achieving family prosperity. Available social support can help individuals to survive.

Families who have children with cerebral palsy can face the pressures that arise with healthy coping, and become stronger and more empowered. Empowered families have more creativity in improving the welfare of their family members. The scope of family empowerment includes the components of family resilience, how the family carries out its functions, roles and duties, managing resources, managing stress and problems, interacting and communicating effectively in their environment. This empowerment is a process of internal empowerment of family members based on the values of love, education and nurturing both characters, social and cultural

education so that it can improve the quality of human resources which aims to create a quality family. The empowerment is facilitated from outside in the form of stimulation and transformation of the value of empowerment which serves as a motivator, so that the family has the self-empowerment to carry out family functions as a family organizational system (Sunarti, 2014).

Conclusion

This study aims to investigate the resilience of families with children with CP and how the environment becomes a part of the family resilience. Families with children with CP have different sources of difficulties and strength, but fulfilling the children with disabilities' therapy and educational needs become the top priority for the family.

The main source of difficulties comes from within the family members. These difficulties lead to other sources of difficulties coming from the surrounding environment or community. Taking care of children with CP requires a lot of time and energy, especially for families with no caregivers because all management activities are carried out by the parents.

Families have to keep adapting to their circumstances by using the source of encouragements that they have to continue carrying out their functions. Each family member has different levels of endurance, but parents are usually the strongest. They support their families by being the internal control centre, having an emotional regulation and belief system, and helping the family to accept their child's condition, so the other family members can reduce their sadness and focus on taking care of their children. All informants channel their sadness and negative emotions into something positive and focus more on their children's treatments.

The sense of responsibility among the family members motivates parents to continue providing care and to work to finance the treatments for their children. Parents' support and supportive relationships with siblings can play a positive role in children's development (Dogbe, Kyeremateng, Opoku, Nketsia, & Hammond, 2019).

The family's ability to continue the treatments for their children must be supported by the environment, including cooperation, commitment, social support, and financial assistance. All of the family's sources of strength help them to continue to take care of their children. Sources of strength come from extended families, communities, acceptance from friendship groups, educational and therapy facilities from *YPAC* (Foundation for Disabled Children), and assistance from the local government. The family will become more motivated to caring for their children when they are well received and supported by the people around them, and it will be easier for them to maintain their resilience.

Family resilience is the primary key to provide a sense of security for children with disabilities. This sense of security can be created when external and internal family factors offer full support to them. This support is present when the nuclear family provides flexibility to Cerebral Palsy Children.

This research has limitations on operational aspects when assisting children with disabilities. For this reason, further research should be expected to develop a new model in service to children with special needs. The case that we raised in this study did not provide more in-depth information about the child protection process, especially the social protection model for Cerebral Palsy Children who need special assistance. Therefore, we hope that further studies on emotional support are strongly influenced by climate change within the family itself.

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Author's Declaration

Authors' contributions and responsibilities
The authors made substantial contributions to the conception and design of the study. The authors took responsibility for data analysis, interpretation and discussion of results. The authors read and approved the final manuscript.

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References

Anshori, A. N. (2020). Jumlah Penyandang Disabilitas di Indonesia Menurut Kementerian Sosial. Retrieved from https://www.liputan6.com/disabilitas/read/4351496/jumlah-penyandang-disabilitas-di-indonesia-menurut-kementerian-sosial

Apostelina, E. (2012). Resiliensi Keluarga pada Keluarga yang Memiliki Anak Autis. *Jurnal Penelitian dan Pengukuran Psikologi, 1*(1), 164–176.

Benzies, K., & Mychasiuk, R. (2009). Fostering Family Resiliency: A Review of the Key Protective Factors. *Child and Family*

Social Work, *6*(14), 103–114. https://doi.org/10.1111/j.1365-2206.2008.00586.x

Bhana, A, & Bachoo, S. (2011). The Determinant of Family Resilience Among Families in Low–and Middle–Income Contexts: A Systematic Literature Review. *Psychological Society of South Africa*, *41*(2), 131-139. https://doi.org/10.1177/008124631104100202

Braga, L. W. & Paz, A. C. (2006). *The Child with Traumatic Brain Injury or Cerebral Palsy*. Taylor & Francis Group

Cichetti, D. & Garmezy, N. (1993). Prospects and promises in the study of resilience. *Developmental and Psychopathology*, *5*(4), 497-502. https://doi.org/10.1017/S0954579400006118

Collins, D. (2009). *An Introduction to Family Social Work* (3 Edition). Brooks/Cole Cengage Learning

Cresswell, J. W. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. SAGE Publications

Cripe, C. T. (2013). Family Resilience, Parental Resilience and Stress Mediation in Families with Autistic Children. Retrieved from https://pqdtopen.proquest.com/doc/1462534031.html?FMT=ABS

Dogbe, J. A., Kyeremateng, J. D. A., Opoku, P. M., Nketsia, W., & Hammond, C. (2019). 'There is family tension, but they understand...': familial and sibling relationships following the diagnosis of cerebral palsy in children in Ghana. *International Journal of Developmental Disabilities*, 1-12. https://doi.org/10.1080/20473869.2019.1573572

Harms, L. (2010). *Understanding Human Development (A Multi-Dimensional Approach)* (2 Edition). Oxford University Press

Hinchcliffe, A. (2007). *Children With Cerebral Palsy*. Sage Publication

Iriani, L. P. & Syafiq, M. (2017). Gambaran hope pada seseorang peyandang tunarungu wicara yang berprestasi. *Character Jurnal Psikologi Pendidikan*, *4*(3), 1-6.

Kalil, A. (2013). *Family Resilience and Good Child Outcomes: A Review of literature*. Ministry of Social Development

Mackay, R. (2003). Family resilience and good child outcomes: an

overview of the research literature. *Social Policy Journal of New Zealand*, *20*, 98–118.

Maulidia, F. N., Kinanthi, M. R., Fitria, N., & Permata, A. S. (2018). Peran koherensi terhadap kepentingan keluarga yang memiliki anak dengan spectrum autistik. *Jurnal Ilmu Keluarga dan Konsumen*, *11*(1), 13-24. https://doi.org/10.24156/jikk.2018.11.1.13

Mawarpury, Marty, dan Mirza. (2017). Resiliensi dalam Keluarga: Perspektif Psikologi. *Jurnal Psikoislamedia*, *2*(1), 96-106. http://dx.doi.org/10.22373/psikoislamedia.v2i1.1829

McCubbin, H. I, McCubbin, A.N., Thompson, I.A., Han, Y-S, & Allen, T.C. (1997). Families Under Stress: What makes them resilient. *Journal of Family and Consumer Sciences*, *89*(3).

McCubbin, H. I. (1979). Integrating coping behaviour in family stress theory. *Journal of Marriage and the Family*, *41*(2), 237-244. https://doi.org/10.2307/351693

McCubbin, H. I., & Patterson, J. M. (1983). The Family Stress Process. *Marriage & Family Review*, *6*(1-2), 7–37. https://doi.org/10.1300/J002v06n01_02

Melani, L. (2014). *Evaluasi Program Terapi Okupasi (Occupational Therapy) Bagi Penyandang Tuna Daksa di YayasanPembinaan Anak Cacat.* Universitas Islam Negeri Jakarta

Myers, H. F. & Taylor, S. (1998). Family Contribution To Risk and Resilience in African American Children. *Jornal of Camparative Family Studies*, *29*(1), 215-229.

Mynarska, M., Riederer, B., & Krivanek, D. (2013). *Vulnerability of Families With Children Major Risks, Future Challenges, and Politics Recommendation.* SAGE Publications

Neuman, L. (2014). *Social Research Methods: Qualitative and Quantitative Approach.* Pearson Education Limited

Nichols, W. C. (2013). Roads To Understanding Family Resilience: 1920s to the twenty-first century. In D.S. Becvar (ed). *Handbook of family resilience.* Springer Science.

Pandanwati, K. S. & Suprapti, V. (2012). Resiliensi keluarga pada pasangan dewasa madya yang tidak memiliki anak. *Jurnal*

Psikologi Pendidikan dan Perkembangan, 1(3), 1-8.

Patterson, J. M. (2002).Integrating Family Resilience and Family Stress Theory.. *Journal of Marriage and Family, 60*(2), 349–360. https://doi.org/10.1111/j.1741-3737.2002.00349.x

Pusat Data dan Informasi Kementerian Kesehatan. (2014). Penyandang Disabilitas pada Anak. Retrieved from http://www.depkes.go.id/download.php?file=download/pusdatin/infodatin/infodatin_disabilitas.pdf

Rahmanawati, F. Y., & Wibowo, D. S. (2017). Resiliensi Keluarga dengan Anak Gangguan Disintegratif Melalui Konseling Kelompok. *Jurnal Penelitian Psikologi, 13*(1), 11-26. https://doi.org/10.32528/ins.v13i1.579

Slaich, V. (2009). *Cerebral Palsy*. Jaypee Brothers Medical Publishers

Smith-Osborn, A. (2007). Life Span And Resiliency Theory: A Critical Review. *Advances in Social Work, 8*(1), 152-168. https://doi.org/10.18060/138

Suharli, S. (2000). *Pentingnya Peranann Keluarga dalam Melakukan Rehabilitasi Sosial Anak-Anak Cacat Diakibatkan Cerebral Palsy (CP) (Studi Kasus terhadap 2 Keluarga di Yayasan Pembinaan Anak Cacat Cabang Jakarta)*. Universitas Indonesia.

Sunarti, E. (2014). *Modul Ketahanan Keluarga Bagi MOTEKAR (Motivator Ketahanan Keluarga di Jawa Barat)*. BP3AKB.

UNICEF. (2013). Anak Penyandang Disabilitas. Retrieved from https://www.unicef.org/indonesia/id/SOWC_Bahasa.pdf

Valentina, T. D. (2014). Penyesuaian Psikologis Orangtua dengan Anak Cerebral Palsy. *Psikologia: Jurnal Pemikiran dan Penelitian Psikologi, 9*(2), 57-64.

Walsh, F. (2016). *Strengthening Family Resilience* (2 Edition). SAGE Publications

Wittenberg, E., Saada, A. & Prosser, L.A. (2013). How Illness Affects Family Members: A Qualitative Interview Survey. *Patient 6*, 257–268. https://doi.org/10.1007/s40271-013-0030-3