# Parenting Children with Autism During the Enhanced Community Quarantine

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Abstract:- Children with Autism (CWA) display difficulty in adjusting to new surroundings and routines. This research aims to identify the difficultiesCWA encountered during the Enhanced Community Quarantine (ECQ) in Baguio and how parents handled the situation. Also, to inform and provide ways for parents who does not have access to other networkon how to handle the situations. Through an online interview, parents were asked to identify the difficulties encountered by CWA during the ECQ in terms of their daily schedule and environment. It also seeks to know if parents encountered any difficulties in handling the situation and how they handledit.

The interview was conducted to 10 parents where6 out of 10 CWA encountered difficulties adjusting to new routines in terms of their sleeping pattern, time schedules and new environment. 5in 10 parents handled it well through explaining the situation, introducing new routines and restructuring the environment; the other 5 encountered difficulties because the quarantine policies does not prohibit the situation, others have work and other children to look after.

Further, the research discussed the differences in the behavior of CWA based on their different age groups. With this, parents will develop an understanding on the needs of CWA and establish ways how to handle sudden changes of schedules and environment. Also, parents will discover varied activities to divert tantrums and meltdowns. Lastly, this research will raise awareness and acceptance in the community that while everybody is striving for coping strategies, these CWA will also be considered.

**Keywords:-** Children With Autism, Enhanced Community Quarantine, Daily Schedules, Environmental Arrangements.

#### I. INTRODUCTION

Lockdown and quarantine have been implemented on different countries of the world as a means of controlling or preventing the increase of the infected cases of the COVID-19 virus. The COVID-19 virus is a new virus linked to the same family of viruses as Severe Acute Respiratory Syndrome (SARS) and some types of common cold [1] or a potentially severe respiratory illness caused by a coronavirus and characterized by fever, coughing, and shortness of breath [2]. In this case, people are advised to stay in their homes to protect themselves from the virus as transmission may happen from person to person.

A lot of people are having a hard time being confined in their homes for a long period of time. Most of the usual routines, activities and work has been disrupted and a lot of adjustments need to be done. Children with Autism (CWA) are one of those having a hard time dealing with these adjustments as change in routines gave them a lot of stress and anxiety. The Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. They often have problems with social, emotional and communication skills. They might repeat certain behaviors and might not want change in their daily activities [3]. However, with the Enhanced Community Quarantine (ECQ), the government's response to prevent person to person transmission, daily activities are about to change. Parents living with CWA are also affected by this situation as they are feeling it twice harder dealing with the pandemic and addressing the needs of their child.

With the changes in the usual day to day activities of people around the world caused by the COVID-19 virus and the emerging cases of mental health issues being reported such as stress, fear and anxiety caused by the lockdown, researches were conducted to help people understand and deal with the situation. Researches provide information and ways about of how to care for one's self – mentally, emotionally and spiritually.

And so, this research was also conducted to identify the challenges of children with autism during the quarantine as they become vulnerable, anxious and stressed when sudden changes are made in their routines and environment. Their vulnerability, anxiousness and stress cause them to display behavioral problems such as tantrums and meltdowns. And so, with the effect of the quarantine to children with autism, parents, as their immediate caregivers, are given a situation to handle. With this, the research also aims to identify the challenges they encountered and their ways of handling the situation.

#### II. REVIEW OF RELATED LITERATURE

This part of the research shows different literatures gathered from research papers and online articles that share information relevant to the research conducted. It discusses the effects of quarantine to children with autism in terms of their routines and environment, it also discusses the importance of routine and predictable environment to children with autism and how to help parents introduce new routines. Also, it includes the difficulties parents living with

children with autism at home and some tips on how to handle difficult situations.

# ❖ Daily Schedules and Environmental Arrangements

Daily schedule and predictable environment are a must for Children with Autism. Many students with autism rely on rules and routines to keep their environment predictable and, therefore, feel safer<sup>[4]</sup>. This a reason why sudden changes are unacceptable for Children with Autism, their daily routine is their way of adapting which helps them be functional, responsive and interactive. Routines help create an efficient environment - they save time. When children know routines, they can perform daily activities more quickly [4]. In an online article, it discusses the importance of routine to children with autism and as to why it is important - (1) routine creates order in their lives, as it creates a safe and secure environment in which life is predictable, (2) routine comes naturally to them, as CWA tend to like repetitive actions, (3) it relieves stress, CWA has a particularly stressful life as he tries to make sense of his surroundings, and (4) routine is a powerful learning tool in the Autism Spectrum Disorder (ASD) environment <sup>[5]</sup>. With the quarantine, being able to follow the same routine and be on a familiar environment is an impossible task for CWA to accomplish which makes them upset or even have an emotional meltdown if the sameness is broken by unexpected changes or people [4].

In order to deal with the sudden disrupted routines during the quarantine, parents must come up with plans on how they are going to introduce new routines and environment. Experts and educators suggest that transitions and changes in daily routines children with autism must be informed ahead of time to know what is going to happen. The following strategies are ways to help parents in introducing new routines which are easy to administer and accessible at home -(1) social stories, using pictures, words or both to describe the new routines or even a way to inform the child why he must stay at home, (2) timetables/visual schedules, to let your child know what to expect, and when, (3) extra time, spending some extra time making the change can help your child feel less anxious, (4) timers, if the child finds it hard to adjust to the new routine, a timer might help as a signal, and (5) slow and steady, if the child finds it hard to switch between activities, try slowly adding new activities, one at a time [6]. Introducing new routines will not be an easy task for parents especially if children are used to their routines for a long period of time but with the proper handling and introduction of new routines CWA will also be able to adjust to the situation.

One thing to remember also in the disruption of routines is the unavailability of therapy sessions for children with autism. The goals of treatment/therapies for Autism Spectrum Disorder (ASD) are to improve core deficits in social communication and social interactions and minimize the impact of restricted behaviors, with an overarching goal to help children develop greater functional skills and independence<sup>[7]</sup>. As it is not possible for parents to send their child to therapies, the fear of regression in the skills of the children with autism is also hard for parents to think.

There is no universally agreed definition for developmental regression; however, all definitions support that regression involves the loss of a previously attained skill <sup>[8]</sup>. And so, without continuous therapy sessions, children may have the tendency to regress on their previously developed skills.

# A. Difficulties Encountered by Parents During the Quarantine

A research study was conducted in Northern Italy, where it aims to find out the psychosocial and behavioral impact of COVID-19 in Autism Spectrum Disorder (ASD) through an online parent survey. Results from this parent survey indicate that the large majority of parent of ASD individuals consider the period of change and restrictions that has followed the onset of the emergency as challenging and requiring more commitment than before [9]. Parents living with CWA are struggling in handling the situation as the needs of their children increased compared from before the quarantine happened. Research findings showed that parents of CWA observed increased difficulties in managing daily activities and behavior problems predicted a higher risk of more intense and more frequent disruptive behavior [9]. Children with autism experience anxiety because of the sudden change in their routines, thus, displaying difficult behaviors for parents to handle. With this, parents as immediate caregivers also experience anxiety caused not only by the change of behavior of their child with autism but of the pandemic, too.

An online article published by PhilStar, a digital newspaper in the Philippines, also discusses the difficulties encountered by parents living with a child with autism. Mayumi Gonzales, a SPED-IE (Special Education-Inclusive Education) and behavior specialist, said that the immediate and more apparent threat posed by COVID-19 to kids with autism is not so much its potential lethally, but rather the unprecedented changes it made to our daily lives [10]. Parents mentioned that their childrenare requiring thrice the attention as changes in behavior were observed brought by the quarantine. Also, with the sudden lifestyle change with no outlet and therapy their child's behavior became so aggressive that they always end up getting hurt [11]. Therapy schedules, consultations, classes and other activities outside the house that may help in the development and improvement in their child's holistic development has been shelved. With this, parents also made their own way of handling these situations through being creative with the activities they provide at home in order to alleviate the anxiety of their child with autism. Parents are left with no option but to think of their own ways to alleviate their kids' pain. On top of the disruption to kids' routines, families face mounting financial pressures and health threats [11].

Parents living with children with autism does not only struggle from trying to close the gaps that the quarantine brought but also to juggle between being an instant homeschool teacher, a caretaker, a mother, and making a living.

#### B. How Parents Handle Difficult Situations

Children with Autism are difficult to handle when there are sudden changes especially during the quarantine. With no one else to turn to, parents are left with no option but to handle the situation and help their child with autism get over their anxieties. For parents of children with special needs, specifically autism spectrum disorder (ASD), a disruption in a well-established day-to-day schedule can lead to fears of meltdowns and steps backward [12]. A lot of articles online are published on how parents can deal with these situations and here is an expert's suggestion on how parents can handle difficult situations at home - (1) set a routine, to develop a schedule, a helpful exercise is to layout the "pre-coronavirus" routine, then identify 2 or 3 habits each day that the child and family can continue. Be sure to allow for more time to engage with each other and for breaks. Breaks are needed for parents and children to help relax the mind. (2) create a child-friendly visual routine, a child-friendly visual schedule is a great tool for children with autism to have so that they know what to expect throughout the day, and can ease any anxiety caused by transitioning to the next activity. (3) continue therapy services at home, pausing occupational, speech and physical therapies can be concerning to parents, who may fear that their child will revert back to destructive or aggressive behaviors. Parents can engage their children to support and motivate their child's development of practical life skills. (4) set home and personal boundaries, during the current quarantine, a parent may be both working and caring for their child(ren). To help your child(ren) separate fun time and work time, allocate certain areas for each. And lastly, (5) don't forget about your self-care [12].

Children with Autism have a fixated day to day routine that they follow and not being able to do this will make them anxious, stress or throw tantrums. If there is a need to change routines it has to be done step by step and slowly until they will be able to adapt to it. However, with the sudden change brought by the quarantine, there would also be a sudden change in the behavior of children with autism. Reviews from the different literatures showed that the quarantine brought anxiety and stress to children with autism as well as to their families. Handling children with autism's behaviors in this quarantine requires more attention and commitment as their need for attention has doubled. Therefore, parents think of ways that helps their child adjust to the current situation.

#### III. METHODOLOGY

## ➤ Research Design

Due to the pandemic and for safety precautions, Google Forms was used for online parent survey through sending the link in messenger. Responses will be automatically recorded in Google Form. Parents were asked for their consent to be a part of the research before answering the parent survey. Also, parents were informed about the purpose of the research and that all information to be given will be kept confidential and will only be used for the purpose of the research.

# > Participants

Ten parents were gathered to be a part of the research as respondents, they were reached through the help of coworkers who are affiliated to parents with children with autism and co-workers who have children with autism. Parents who joined the research are the immediate caretakers who knows the day to day activities of their children and can identify the changes displayed from before the quarantine and during the quarantine.

#### > Instrument

The questions provided in the parent survey were based from articles which discusses the commonly observed changes in children with autism during the quarantine [13]. The method of collecting data was mainly qualitative as it gives more concrete explanation of the changes in the activities of children with autism's behavior during the quarantine and how their parents handled the situation. The survey consisted of 8 open-response questions divided into 2 sections – information (name of respondent, relationship to the child, age of child, grade level, clinical diagnosis) and research questions (difficulties/adjustments in terms of schedule and environment, difficulties in handling the situation, how situations were handled).

#### ➤ Analysis

Responses were transcribed and thematic analysis was conducted to identify responses that share the same context. The information gathered presents the number of CWA who experiences the same difficulties and adjustments encountered during the quarantine as observed by their immediate caretakers. Also, the difficulties encountered by parents in handling the situation and how they handled it. Responses given were evaluated whether it is consistent or inconsistent to the questions given. In cases that the response was deemed inconsistent it will be discarded and will not be presented in the results.

### IV. RESULTS AND DISCUSSION

The research conducted has a total of 10 respondents who are the mothers of children with autism and the immediate caretaker during the quarantine. The mean age of the children is divided into 3 groups: Group 1 has 3 participants with the mean age of 5, all of them are not attending school and are diagnosed with ASD; Group 2 has 3 participants with the mean age of 10.67, all are in grade school, 2 are diagnosed with ASD and 1 has ASD with the comorbidity of Learning Disability and Group 3 has 4 participants with the mean age of 19.5, 2 are in higher grade level and 2 are enrolled in the Transition Program and all are diagnosed with ASD.

# ➤ Daily Schedules

Out of the 10 respondents, 6 responses were acknowledged while 4 was discarded as it was inconsistent with the question provided. The result gathered presents 3 themes which shows the most commonly observed changes in the daily schedule of CWA during the quarantine - (1) sleeping pattern, where the child was observed to sleep later than the usual sleeping schedule which even resulted

tantrums, shouting and self-inflicted pains, (2) time adjustment for online classes, where parents decided to make visual schedules to be followed and (3) as normal,

usual activities did not change as child is used to staying at home.

Table 1: Response about the difficulties/ adjustments encountered by CWA during the quarantine in terms of their daily schedule

Daily Schedule	No. of respondents	Age Group
Sleeping Pattern	1	Group 1
Time Adjustment for Online Classes	3	Group 2/ Group 3
As normal	2	Group 2/ Group 3

Table 1 shows that 1 in 6 children struggles with sleeping belongs under group 1 that has the mean age of 5. Sleep problem is commonly observed in children with autismespecially in younger age groups. A 2019 study, one of the largest to investigate the prevalence of sleep problems in autism, suggested that nearly 80 percent of autistic preschoolers have disrupted sleep<sup>[14]</sup>. Children with autism who have sleep problems usually display behavioral problems such as tantrums and meltdowns. In a study conducted, one precipitating factor in sleep problems of children with autism is the environmental stresses such as changes in evening routines and sensory stimuli [15]. And so, with the quarantine and changes in daily schedules sleep problem would commonly be observed in CWA especially those in the younger age group. In other age groups, under group 2 with the mean age of 10.67 and group 3 with the mean age of 19.5, as they are all enrolled in an online class the common problem encountered was on how they would adjust their class schedules in their usual home routines. Home and school have different daily routines and trying to put them together would put them into confusion and would have trouble adjusting which can have a very negative effect on the child's behavior. Negative reactions will occur in the form of screaming, tantrums, pushing, and occasional

violent behaviors. Sometimes, the child will be inconsolable. These extreme reactions are due to the increased stress, fear, and anxiety that arise due to changes in a familiar routine that make them feel less safe and secure<sup>[16]</sup>.Lastly, 2 CWA under the age group 2 and 3 did not have any trouble with adjusting to their daily routine. This could happen as well especially if they spend most of their time at home rather than in school or if they find it more comfortable to be staying at home. The environment always plays a great factor in adjustment, as long as they feel safe and secure in their environment adjustment in their daily routine would not be a problem.

# > Environmental Arrangements

Out of the 10 respondents, 6 responses were acknowledged while 4 was discarded as it was inconsistent with the question provided. With this, 4 themes were presented which shows the adjustments CWA encountered in their environmental arrangement during the quarantine as observed by their immediate caretakers – (1) set up sensory corners with sensory light lamp to lessen anxiety, (2) goes outside to play/ made a play space inside the house to lessen boredom, (3) prepared a study area, and (4) engaging to community activities.

Table 2: Response about the difficulties/ adjustments encountered by CWA during the quarantine in terms of their environmental arrangements

Environmental Arrangements	No. of Respondents	Age Group
Set up sensory corners with sensory light lamp	1	
Goes outside to play/ made a play space inside the house	2	Group 1
Prepared a study area	2	Group 2 / Group 3
Engaging to community activities	1	Group 3

In Table 2, children with autism under age group 1 encountered adjustments in the need to improve their environment through setting up sensory corners with sensory light lamp, which has 1 respondent, and the need to put up a play space with 2 respondents. Autism is commonly accompanied by sensory issues. The American Psychiatric Association even added sensory sensitivities to the list of symptoms that help diagnose autism in 2013 [17]. With the sudden changes in their daily routine CWA are having tantrums and meltdowns, and so, with the help of play and sensory items it will help them relax, focus better, and calm down. Children under the younger age find sensory toys and play a good way to deal with stress during the pandemic as it helps them to adjust and calm down. CWA who are enrolled in online classes under age groups 2 and 3, need to

set up study areas at home, this is to let them have a dedicated room as their safe space, a choice of occupations and uninterrupted homework time [18]. With this, having a safe space at home would not cause any problem with the adjustment in the changes due to the quarantine. Lastly, one respondent under age group 3 finds engaging to community activities as a way to keep himself calm during the quarantine. Older age groups can easily communicate what they need in order to address their needs as compared to CWA under the younger group.

# > Difficulties Encountered in Handling the Situation

Out of the 10 responses, 5 parents mentioned they did not encounter any difficulties while 5 parents encountered difficulties in handling the situation. Parents who did not

encounter difficulties mentioned that explaining the situation to them, keeping them busy by giving activities to do and comforting them are enough to pacify their anxiety. On the other hand, parents encountered difficulties because their children ask for more space and a new environment where it is hard to provide since the quarantine requires every to stay at home. Also, looking after CWA requires more attention and guidance which is hard to give since parents are working and has other children, too.

#### ➤ How Parents Handled the Situations

Out of the 10 responses, 9 responses were acknowledged while 1 response was discarded due to inconsistency to the question given. With this, 5 themes were presented on how parents handled the situation they encountered – (1) taught child to help in household chores, (2) get advices from support group, (3) pays visit to neighbors or town to socialize and to have a new environment, (4) gave activities to keep child busy, and (5) explained the situation.

Table 3: Responses on Difficulties Encountered and How Parents Handled the Situations

Difficulties Encountered in Handling the Situation	How Parents Handled the Situations	
Requires more attention and guidance	Taught child to help in household chores	
	Gave activities to keep child busy	
Ask for more space and a new environment	Pays visit to neighbors or town to socialize and to have a new environment	
Others	get advices from support group	
*parents who did not encounter difficulties	explained the situation	

Results in Table 3 shows the difficulties encountered by parents and the way they handled it. For children requiring more attention teaching kids to do household chores to keep them busy would make them feel less anxious. Children under age group 1 are the ones who usually requires more attention and guidance as it is hard for them to communicate their needs. Teaching CWA to do household chores would help them to be more independent and gain confidence in caring for themselves. As for CWA, there is a need to do task analysis, modification of tasks and prompting when teaching them household chores [19]. Teaching them may take a lot of time but it helps them adjust and calm. Teaching children with practical skills at home is also a means of continuing therapy services at home such as occupational and physical therapies to avoid reverting back to destructive or aggressive behaviors<sup>[12]</sup>. Parents also encountered difficulty in providing a new environment for their children because with the quarantine policies unnecessary trips outside the house is prohibited. Other parents may find it unnecessary but for parents living with CWA it is necessary to bring out their CWA to lessen their anxiety of being locked up inside their home. And so, parents in this research made ways to handle the situation such as to bring their child in the neighborhood as it is closer and would give a new environment for their child and lessen anxiety or bring them to town during their market day schedule. Other parents in some interviews bring their child for a ride around the neighborhood and just hopes that they will not get caught by the authorities [11]. On the other hand, parents who were able to handle the situations well suggested that getting a support group would help in dealing with the needs of CWA during the pandemic. Support groups enable parents to share information with one another, such as information about therapies or new programs, stories and experiences of living with autism, and advice on how to deal with different professionals. They also allow parents to vent their frustrations, and have their feelings validated and understood<sup>[20]</sup>. Also, for CWA under age group 3, parents were able to explain to them the

situation which made it easy for them to handle the situation. Experts also support this idea, Mohiuddin, a child and adolescent psychiatrist, suggests that explaining the situation would help them understand the situation and reinforces key concepts like how to protect themselves from the virus [21].

#### V. CONCLUSION

The Enhanced Community Quarantine brought a great impact in the life of Children with Autism as well as their families. Adjustments in schedule and the environment gave children with autism anxiety and stress; they insist upon the same routine or environment and be upset or even have an emotional meltdown if the sameness is broken by unexpected changes or people [4].Results in the survey conducted showed that in the sudden change of schedule and environment Children with Autism are anxious resulting to changes in behavior such as tantrums, shouting and self-inflicted pains, which on the other hand, requires more guidance and attention from parents. Thus, application of rules and routines in school and home are important to help children with autism engage more successfully in activities and prevent problem behavior<sup>[4]</sup>.

Parents of children with autism are the ones managing the adjustments encountered by their children. And so, parents also encounter difficulties as to how they would handle the situation they are in. In this way, parents made creative ways to address the needs of their children such as teaching them to do household chores to keep them busy to avoid getting anxious when bored. They pay visits to neighbors just to have a new environment which is also a type of therapy in developing socialization and communication skills. Also, through getting advices from a support group which experiences the same situation and for children who is able to understand the situation explaining the situation through watching news and answering their questions are ways to handle the situation

In conclusion, children with autism have their own needs and ways of adjusting depending on their age groups. CWA under younger age groups have trouble sleeping and finds it harder to adjust in their environment while CWA under in a much older groups finds it easier to adjust because they can communicate their needs. Parents, on the other hand, has their own ways of handling their situation based on the needs of their children.

#### VI. LIMITATIONS AND RECOMMENDATIONS

The research was conducted during the quarantine and being able to get respondents in this situation and shows results would mean that succeeding researches to meet the gaps of this research is possible. The survey conducted is limited in terms of its respondents which is not enough to represent a big number of CWA in a local area and questions presented were not enough to encompass all of the challenges and difficulties in the struggles and adjustments of CWA and their families during the quarantine. However, even with limitations the research results presented enough information and met the objectives of the research which is to identify the effect of quarantine to CWA and how parents, as immediate caretakers, handled the situation.

And so, should there be researchers willing to make further research regarding the effects of the quarantine to CWA and how parents handled them, the researchers would like to recommend the following to strengthen the reliability and validity of the research - (1) conduct a research to a larger number of respondents, (2) create a questionnaire that encompasses all the possible challenges and difficulties of CWA and (3) an action research is better than a qualitative research.

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