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APPENDIX 1

Ethical Clearance Certificate

Tezpur University Ethics Committee
Tezpur: 784028 : Assam

Communication of Decision of Tezpur University Ethics Committee (TUEC)

IEC No: DoRD/TUEC/PROP/2022/13-R1

Protocol title: Psychosocial Intervention for Mothers of Children with Autism Spectrum Disorder-A randomized control trial		
Principal Investigator: Ms. Mona Alice Marbaniang		
Name & Address of Institution: Tezpur University, Tezpur, Assam 784028		
<input type="checkbox"/> New review	<input checked="" type="checkbox"/> Revised review	<input type="checkbox"/> Expedited review
Date of review (D/M/Y): 16-02-2023		
Date of previous review, if revised application: 29-09-2022		
Decision of the IEC/IRB:		
<input checked="" type="checkbox"/> Recommended	<input type="checkbox"/> Recommended with suggestions	
<input type="checkbox"/> Revision	<input type="checkbox"/> Rejected	
Suggestions/Reasons/Remarks: The proposal is recommended for approval.		
Recommended for a period of: One (01) year with provision of extension subjected to submission of satisfactory report		

Please note

- Inform TUEC immediately in case of any adverse events and serious adverse events
- Inform TUEC in case of any change of study procedure, site and investigator
- This permission is only for period mentioned above. Annual report to be submitted to TUEC
- Members of TUEC have right to monitor the trial with prior intimation

Date: 21/03/2023

Signature of Chairperson (with seal)

TUEC

Chairperson
Tezpur University Ethics Committee

APPENDIX 2
Participant Information Sheet
(Phase 1: Needs Assessment)

Title of the study: Psychosocial Intervention for Mothers of Children with Autism Spectrum Disorder – A Randomized Controlled Trial

Name of the Principal Investigator: Mona Alice Marbaniang (Ph.D. Scholar, Department of Social Work, Tezpur University)

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

The Aim of the study is to examine the effects of a psychosocial intervention for mothers of children with autism spectrum disorder (ASD) on their overall quality of life.

The proposed study is to explore and understand the needs, stress, types of social support and coping strategies of mothers whose children has been diagnosed with Autism Spectrum Disorder. Subsequently, a psychosocial intervention based on those needs and challenges will be provided to the mothers. The study will be conducted in the centres in which your child is attending.

Subsequent to your consent to join this social research activity, you would be requested to answer a few instruments dealing with parenting stress, social support and coping strategies. Answering these instruments would approximately take 30-45 minutes. Your participation is voluntary; it does not carry any monetary or material benefits there upon. You can refuse to participate or withdraw your consent and stop taking part in the study or answering the questions at any point of time.

Furthermore, the data collected will be kept secured and will only be accessed by the researcher. Confidentiality will be maintained all throughout the research process.

The results of the study will help both the mothers and the service providers to understand the different psychosocial challenges associated with having a child with autism which will further help the mothers in managing stress, enhancing social support and build adaptive coping skills.

Undertaking by the investigator:

Your consent to participate in the above study is sought. You have the right to refuse consent or withdraw the same during any part of the study. If you have any doubts about the study, please feel free to clarify the same by contacting Ms. Mona Alice Marbaniang (Contact No. 8761812702), Principal Investigator & PhD Scholar, Social Work Department, Tezpur University. Investigator has the right to terminate the subject's participation if not liable for the study requirements. Confidentiality will be highly maintained.

Thank You

APPENDIX 3

Informed Consent:

I have been informed and explained about the purpose, procedures and confidentiality of the study. I have been explained that there are no potential risks for participating in the study. My participation in the research is voluntary. I have understood that I have the right to refuse my consent or withdraw it any time during the study. I am aware that by subjecting to this investigation, I will have to give more time for assessments by the investigating team and that these assessments do not interfere with the benefits to which I may be entitled. I also understood that, the information will be used only research purpose and will be kept confidential. I have no tangible benefit by participating in the study.

I,, the under signed, give my consent to be a participant for this study.

Signature of the Respondent

(Name and address)

Signature of the Witness

(Name and address)

Signature of the Investigator:

APPENDIX 4

Interview Guide

(Phase 1: Needs Assessment)

Respondent No:

1. Current Age:
2. Age of mother when child with autism was born:
3. Age of father when child with autism was born:
4. Education:
5. Religion:
 - 1) Christianity
 - 2) Hinduism
 - 3) Islam
 - 4) Others
7. Marital status:
8. Employment status of mother:
9. Employment status of father:
10. Family Type:
 - 1) Nuclear
 - 2) Joint
 - 3) Separated
 - 4) Extended
11. Gender of the child with Autism:
 - 1) Female
 - 2) Male
12. Age of child with autism:
13. If more than one child with Autism:
14. Family History of autism if any:
15. Who is the earning member? Through father's pension
16. Family income (Kuppuswamy)-
17. Number of children:
18. Total No. of family members:
 - What do you understand about autism? Have you heard of Autism before?
 - What were the first symptoms of your child that raised your concern and at what age?
 - When was the child diagnosed? What did you do/ what step did you take after your child was diagnosed?
 - What other alternative treatment did you try before enrolling in this centre?
 - Do you get help/assistance from your spouse/other family members in primary caregiving for the child?
 - What are the attitudes of other family members towards you or your child?

- Do you feel overburdened with the responsibilities of caregiving? Do you feel emotionally drained from caregiving?
- Do you have time for extra leisure activities for yourself?
- Do you feel the need to take a break from your responsibilities?
- Do you face any kind of stigma from society/relatives?
- What are the different problems you face because of this stigma?
- As a primary caregiver, what stresses you out the most?
- What are your sources of support, are these easily available and accessible?
- How do you cope with stress?
- Do you feel the need to get extra help in behavioural management of your child apart from the help received from the centre?
- What are your concerns regarding the child's future?
- What's your routine when you go back home now?

APPENDIX 5
Participant Information Sheet
(Phase 2: Implementation of Intervention)

Title of the study: Psychosocial Intervention for Mothers of Children with Autism Spectrum Disorder – A Randomized Controlled Trial

Name of the Principal Investigator: Mona Alice Marbaniang (Ph.D. Scholar, Department of Social Work, Tezpur University)

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

The Aim of the study is to examine the effects of a psychosocial intervention for mothers of children with autism spectrum disorder (ASD) on their overall quality of life.

Family members of children with autism often experience negative psychological wellbeing. They are at a higher risk for depression, social isolation and marital discord. Some go through periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt. These may worsen when the caregivers do not receive support. The overall aim is to provide guidance and assistance for you in addition to the treatment or therapies that you and your child are receiving from this center. Participating in this intervention plan will help you in the current situation as well as in the long run. I will be explaining in detail about the intervention procedure as follows:

In total there will be 11 sessions, of which each session will require 45 minutes to 1 hour of your time. The session will be done 3 days in a week, of which a gap of one day will be taken after each session. So overall, this will be completed in approximately 8 to 10 days. The session can be carried out on the days and time which would be convenient for you.

Let us go through the steps in detail:

Step 1: Intake and pre-assessment- in this first session, I would like to know about some personal details and the current situation. I will also be using 3 questionnaires that will assess your stress, support and coping behaviors.

Step 2: Enhancement of knowledge regarding Autism- in the second session, we will discuss the nature of Autism, its signs and symptoms, the different treatment modalities and the importance of treatment adherence.

Step 3: Addressing stigma- in this session, we will discuss about the causes of stigma and discrimination and how to overcome them.

Step 4: Building and Strengthening Support System- in this second session, we will discuss the importance of support systems, how to identify them and how to efficiently seek the available support.

Step 5: Enhancement of Helpful Coping Behaviors- in this session, we will first try to understand various types of coping, then we will assess if your current ways of coping are helpful or unhelpful to the situation then we will try to find alternative ways of coping responses if needed.

Step 6: Dealing with emotional distress- in this session, we will discuss the causes of emotional distress and you will learn how to do simple relaxation techniques in order to deal with the stress.

Step 7: Management of child's challenging temperaments- in this session, we will try to understand the reasons behind the behavioral and communication challenges and we will learn some basic tips on how to manage them.

Step 8: Termination and Future Plan- here we will summarize what all we have learnt throughout the previous sessions in brief.

Furthermore, your participation is voluntary; it does not carry any monetary or material benefits there upon. You can refuse to participate or withdraw your consent and stop taking part in the study or answering the questions at any point of time. The information collected will be kept secure and will only be accessed by the researcher. Confidentiality will be maintained all throughout the research process.

If you are willing to participate, you are required to sign the consent form below.

Informed Consent:

I have been informed and explained about the purpose, procedures and confidentiality of the study. I have been explained that there are no potential risks for participating in the study. My participation in the research is voluntary. I have understood that I have the right to refuse my consent or withdraw it any time during the study. I am aware that by subjecting myself to this investigation, I will have to give more time for assessments by the investigating team. I also understood that the information will be used only for research purposes and will be kept confidential. I have no tangible benefit by participating in the study.

I,, the under signed, give my consent to be a participant for this study.

Signature of the Respondent

(Name and address)

Signature of the Witness

(Name and address)

Signature of the Investigator:

Undertaking by the Investigator:

Your consent to participate in the above study is sought. You have the right to refuse consent or withdraw the same during any part of the study. If you have any doubts about the study, please feel free to clarify the same by contacting Ms. Mona Alice Marbaniang (Contact No. 8761812702), Principal Investigator & PhD Scholar, Social Work Department, Tezpur University. Thank You

APPENDIX 6

Multidimensional Scale of Perceived Social Support

(Zimet, Dahlem, Zimet& Farley, 1988)

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree**

Circle the “4” if you are **Neutral**

Circle the “5” if you **Mildly Agree**

Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

APPENDIX 7

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out you were going to have this situation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.

16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

APPENDIX 8

Parental Stress Scale

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1	I am happy in my role as a parent	Choose one
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	Choose one
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	Choose one
4	I sometimes worry whether I am doing enough for my child(ren).	Choose one
5	I feel close to my child(ren).	Choose one
6	I enjoy spending time with my child(ren).	Choose one
7	My child(ren) is an important source of affection for me.	Choose one
8	Having child(ren) gives me a more certain and optimistic view for the future.	Choose one
9	The major source of stress in my life is my child(ren).	Choose one
10	Having child(ren) leaves little time and flexibility in my life.	Choose one
11	Having child(ren) has been a financial burden.	Choose one
12	It is difficult to balance different responsibilities because of my child(ren).	Choose one
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	Choose one

APPENDIX 9



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Psychosocial Intervention for Mothers of Children with Autism Spectrum
Disorder (ASD): A Randomized Controlled Trial

Introduction

Parenting is often described as one of life's most rewarding experiences, offering profound joy and fulfillment. The process of nurturing a child, guiding their development, and witnessing their growth and achievements is a source of immense pride and satisfaction for many parents. However, parenting also comes with its fair share of challenges. The demands of raising a child can be overwhelming, involving significant emotional, physical, and financial investments. Balancing the needs of the child with personal responsibilities, maintaining a healthy family environment, and ensuring the child's overall development can create a complex and often stressful experience for parents.

When a child has special needs, the challenges associated with parenting can become even more pronounced. Special needs children often require additional attention, specialized care, and tailored support, which can place additional strain on parents. The emotional and psychological impact of dealing with a child's special needs can affect the entire family dynamic, including the parent's mental health and overall quality of life. This heightened stress is often compounded by societal pressures, stigma, and the perceived inadequacy of existing support systems.

Overview of Autism Spectrum Disorder (ASD)

In 1912, Paul Eugen Bleuler who is a Swiss Psychiatrist, first used the term "autism" in the *American Journal of Insanity*. He based the term on the Greek word "autos," meaning "self," to describe what he identified as a form of schizophrenia manifesting in childhood, a condition he also named (Blake et al., 2013). Among his patients, he observed tendencies towards social withdrawal, diminished interest in others, and difficulties in effective communication (Zanderer, 2023). It was not until the 1940s that autism gained recognition as a distinct condition. In 1943, American psychiatrist Leo Kanner published a seminal paper titled "Autistic Disturbances of Affective Contact" in the journal *The Nervous Child* (Blake et al., 2013) outlining a group of 11 children, comprising eight boys and three girls aged between 2 and 8, who consistently exhibited a strong inclination towards solitude since infancy. These children

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