WEST VIRGINIA
AUTISM TRAINING CENTER
AT MARSHALL UNIVERSITY

West Virginia Autism Training
Center Informed Consent Agreement
2021

The following Consent Agreement outlines several types of services or activities that may be made available to you, your child, or your family member by the West Virginia Autism Training Center (WVATC, or "agency"). Please read each statement carefully and be certain you understand the statements before consenting to participate in services provided our agency.

Page 5 includes designated space to initial each section in which you give consent, a space to provide explanation for activities for which you do not provide consent, and a designated space for your signature. Consent is not time limited. If you wish to withdraw consent after it has been given, please contact Dr. Marc Ellison at the address below.

Please complete, then return Page 5 to us in the self-addressed stamped envelope provided. For questions, please contact:

Dr. Marc Ellison, Ed.D., LPC
Executive Director
West Virginia Autism Training Center
Marshall University
One John Marshall Drive
Huntington, West Virginia 25755
304-696-2332 or 800-344-5115

Consent for Services

(1.) I understand the purpose of the WV ATC is to provide educational and information services to families, individuals and educators. These services may include but are not limited to receiving library materials, in-service trainings, special topic trainings, family coaching and direct services.

- I understand that there is no guaranteed time by which I, my child, or my family member will be selected for direct services.
- I understand I must be willing to make a commitment to work intensively with others who support my child in school, work or other community programs while participating.

(2.) I understand I am free to withdraw as a registered client at any time without penalty to me, my child, or my family member.

(3.) I consent to allow staff of the WV ATC to observe me, my child, or my family member should such an observation be deemed necessary by both parties.

(4.) I understand the WV ATC is not responsible for any fees or charges that result from additional assessments, i.e. medical exams, even if these evaluations are recommended by WV ATC.

(5.) Participation in any service may involve some risk, including the loss of confidentiality. I understand the WV ATC will take all reasonable precautions to ensure confidentiality as prescribed by law.

(6.) The direct service programs are based on a body of literature which supports the notion that caregivers are vital components for the positive prognosis for their children.

(7.) The WV Autism Training Center staff are mandated to report to Child or Adult Protective Services should they obtain knowledge of or suspect abuse or neglect.

(8.) You are free to question the use of any procedure, and you may request that a specific procedure(s) not be used. Any procedure in question will be terminated upon your request even after the procedure has started. Your request for termination of a specific procedure(s) will not affect you or your child's continued participation in the direct service program.

(9.) You are free to withdraw your consent at any time without penalty to you or your child. You will still be eligible for other services and programs offered by the WV ATC.

(10.) As with any service program, there is a chance that the program will not produce any significant behavioral changes for you, your child or family member with autism or your family. There is also a risk of behavioral deterioration with children who present serious challenging behaviors. Should serious challenging behaviors, which may result in injury, occur, you should seek medical attention immediately.

(11.) In the event of injury or illness as a result of participating in this program, neither the WV ATC, nor Marshall University shall be held responsible. The costs of medical care will be your responsibility.

(12.) Also, the time commitment for attending meetings and training and implementing behavioral procedures at home may be viewed as disruptive to normal family schedules. All efforts to accommodate family schedules will be made.

(13.) This consent allows the WV ATC to alert school personnel (special education director, principals, and teachers) that we will be providing support to your child and will be inviting them to participate.

Note: For questions about your rights as a participant in the evaluation research component of the program, contact Marshall University IRB# 2 Chairman Dr. Stephen Cooper or the Office of Research Integrity at 304-696-4303. You may also call this number if:

- You have concerns or complaints about the evaluation research component of the program
- The WV ATC staff cannot be reached to answer questions about the evaluation component of the program
- You want to talk to someone other than the WV ATC staff about the research evaluation component of the program.

Consent for Media

I consent to allow the WVATC to create digital audio or video recordings or take photographs of me and/or my child or family member with my permission. I understand recordings and/or photographs may be used for training others to work with and understand persons with ASD, to increase public awareness, or be used in scholarly or training activities. I understand my name and the names of those in my family will be kept confidential.

I understand that I have no authority to amend the content of visual or auditory media. Further, I understand that I have no legal right to any financial remuneration from this experience.

I understand I will be alerted prior to the use of media in which I, my child, or my family member is involved. I also understand I may revoke this *Consent for Media* permission at any time during my relationship with WV ATC.

Consent for Release of Protected Health Information for Research Purposes

The WV ATC evaluates the outcomes of each direct service. By participating in the direct service programs, you have been asked to participate in an evaluation research study under the direction of Dr. Marc Ellison, Executive Director of the WV ATC at Marshall University, and his research evaluation team. The purpose of this study is to evaluate outcomes resulting in participation in the direct service program for your family and child with an autism spectrum disorder. The program will result in the formation and development of a support plan for your child which will focus on increasing adaptive behaviors, decreasing challenging behaviors and increasing your child's and family's quality of life.

By signing the Patient Authorization section of this consent, you are agreeing to the use and disclosure of your PHI (Protected Health Information) as described in this Patient Authorization, to provide Dr. Marc Ellison and his evaluation research team access to the following information about you and your child with an autism spectrum disorder:

1) Demographic information (i.e. county of residence, marital status, educational placement of your child, age and diagnosis of your child)
2) Your scores on the Questionnaire on Resources and Stress before and after the program
3) Your scores on the Behavior Rating Scale before and after the program.
4) Your ratings of your child's quality of life, before and after the program
5) Your child's baseline and intervention data on behaviors targeted for change by your child's team

If you do not sign this authorization, we will implement the direct service program but will not be able to evaluate or share outcomes for your child and family. This authorization has no expiration date.

You can revoke this authorization at any time. To revoke your authorization, you can write to Dr. Marc Ellison or you can ask a member of the research evaluation team to give you a form to revoke the authorization. If you revoke this authorization, we will not evaluate outcomes resulting from participation in the program.

If you revoke this authorization, Dr. Marc Ellison and his research evaluation team can continue to use the information that has been collected. No information will be collected after you revoke the authorization.

As part of the direct service programs, we may use the outcome data collected to analyze the effectiveness of the program. These data will be group data and there will be no identifiable information included. These data may be shared with the public through research articles. We will not disclose identifiable information without separate written consent from you.

This study includes the creation of a database of information collected such as the Questionnaire on Resources and Stress and the Behavior Rating Scale for you and your child that could be used in future evaluation research. No names are used to identify you or your child to anyone other than the research team. By signing this authorization, you agree to allow the information collected in this study to be added to that database.

You have a right to obtain access to your PHI collected or used as part of this research evaluation study. Behavior change data will be shared among your child's team. If you wish to have access to your additional PHI, send a written request to Dr. Marc Ellison. By signing this Patient Authorization, you have not waived any of your legal rights.

For Office Use Only
Client #: _____

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Informed Consent Checklist and Signature Page

Please initial beside the category for which you provide informed consent. If you wish to withhold consent, or modify your consent in some manner, please explain your intention in the space provided. Consent is not time limited. If you wish to withdraw consent after it has been given, please contact Dr. Marc Ellison. **After completing and signing this form, please return this page to WV ATC in the envelope provided. Please keep all pages <u>other than</u> this signature page for your records.**

<u>Please note:</u> Your signature on this form specific to the direct service programs provides your consent to participate in these programs, and allows WV ATC to exchange information with schools or other institutions that serve the client.

Consents:	**Your initials for approval**
Consent for Services	_____
Consent for Media	_____
Consent for Release of Protected Health Information	_____

Requested consent exceptions: _____

_____

_____

Client Name (printed) _____

Legal Guardian (printed) _____

Legal Guardian Signature: _____ **Date:** _____

WV ATC Director or Designee: _____

WEST VIRGINIA
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For Office Use Only

Client#_____

Registration for Services

Name of Individual: _____ Date: _____

Date of Birth: _____ Diagnosis: _____ Gender: ____ Male ____ Female

Ethnicity: _____ Caucasian _____ Black or African American

_____ Asian _____ Hispanic or Latino

_____ Other If other please specify: _____

Mailing Address: _____

(If different from mailing)

Residence Address: _____

City: _____ State: _____ Zip: _____

County of Residence: _____ Email: _____

Primary Phone: _____ Secondary Phone: _____

Name of Parent(s)/Legal Guardian(s): _____

Relationship to Applicant: _____ Parent(s) _____ Grandparent(s)

_____ Self _____ Foster parent(s) _____ Other

If other please specify, Sibling or Agency: _____

_____

Is this your first application for services: _____ Yes _____ No

If no, what year(s) did you receive services: _____

Education

Does the individual currently attend school: Yes _____ No _____

If yes, name of school: _____ Current grade: _____

Current plan in place for the individual: IFSP_____ IEP _____ 504 _____

Intervention Specialist: Yes _____ No _____ Personal Aide: Yes _____ No _____

Assistive Technology: Yes _____ No _____ Classroom Aide: Yes _____ No _____

Occupational Therapy _____ Physical Therapy _____ Speech Therapy _____

Other _____ If other please specify: _____

Please list other Agencies or Centers currently involved: _____

_____

Types of services receiving: _____

_____

Transition

Does the individual with ASD have a transition in the next year:

Pre-K _____ Kindergarten _____ Middle School _____ High School _____

College _____ Employment _____ Independent Living _____ Other _____

If other please specify: _____

_____

Communication

Is the individual: Verbal _____ Nonverbal _____

If nonverbal what other forms of communication are used: _____

_____

Please check areas of concern:

_____ Understands and follows verbal instruction

_____ Using communication for social purposes

_____ Difficulties following rules of conversations, such as turn taking during discussions

_____ Understanding inferences or something that is not explicitly stated

_____ Uses words to express wants and needs

_____ Using technology for communication as needed (Text, Email, Facetime, Social Media)

Social

Please check areas of concern:

_____ Maintaining appropriate personal space during conversations

_____ Initiating or returning greetings with peers

_____ Demonstrating turn-taking skills during daily activities

_____ Showing interest or curiosity in others

_____ Playing with peers and sharing toys/materials with others

Sensory

Please check areas of concern:

_____ Being touched, hugged, cuddled

_____ Certain clothing, fabrics, seams, tags, shoes

_____ Trying foods with new textures, tastes, temperatures

_____ Problems with sounds, lights, crowds, etc.

_____ Feels, smells, tastes objects in the environment

_____ Ability to recognize anxiety or stress and calm self as needed

Behavior

Please check areas of concern:

_____ Severe temper tantrums or meltdowns

_____ Elopement (running away)

_____ Refusal to complete task/follow directions

_____ Self-injurious behaviors (hitting self)

_____ Aggression (hitting others, destroying materials, verbal threats)

Daily Living Skills

Please check areas of concern:

_____ Toileting

_____ Self-care awareness: dressing, grooming, hygiene

_____ Follows transitions and daily routine

_____ Difficulty recognizing and understanding dangerous situations

Independent Living Skills

Please check areas of concern. Mark "NA" if the activity does not apply

_____ Knows who to seek or call for assistance in an emergency

_____ Being aware and having the understanding of self-advocacy

_____ Using appliances and household products as needed

_____ Responsible for cooking and preparing meals as needed

_____ Able carry out home maintenance responsibilities and or work related chores

_____ Managing time, maintaining schedules and sleep, and waking self as needed

_____ Able to navigate neighborhood, walking to and from local destinations

_____ Able to shop as needed in grocery or retail environments

_____ Making purchases, handling money, checkbook or ATM/credit cards

_____ Transportation: riding buses or cabs, driving a motor vehicle

_____ Building relationships and or interested in dating

_____ Interested in pursuing a college degree or employment

Please list any other information that you feel is important for us to know:

_____

_____

_____

_____

_____

_____

_____

_____

_____ _____

Signature of Parent/Legal Guardian/Self Date