



Description of FBRI Neuromotor Research Clinic Services

Explanation of Procedures

If your child participates in our clinical program it will involve **Intensive Therapy based on ACQUIRE Therapy**. The program will be designed to meet your child's needs, and we will provide therapeutic services for multiple hours each day across multiple weekdays for several weeks. Our goal will be to promote the functional use of your child's weaker motor skills and/or to promote developmental progress in other developmental domains. We will decide with you the daily and total number of hours your child receives.

The ACQUIRE approach is described below:

Your child will receive intensive/individualized treatment/therapy between 3 to 6 hours a day for up to 20 days for a 2-4 week period of time. Therapy occurs Monday – Friday. We will discuss with you the specific number of hours of therapy that your child will receive. We will provide a recommendation based on our previous experiences, but we also want your input regarding what you believe might be appropriate for your family. If your child has trouble with the intensity level at the start of treatment, an attempt may be made to try and extend his/her endurance during the entire treatment period. If your child becomes ill during the treatment process you will not be billed for the hours or days of treatment missed, however we do ask that you contact your therapist if your child has signs of a contagious illness (such as vomiting or fever) within 24 hours of the next treatment session. If the therapist becomes ill during the treatment process, another therapist may be assigned, but we will do everything possible to minimize treatment disruptions. Therapy may occur in your home or in other natural settings, such as in a preschool setting, or relative's home. Where your child receives daily therapy will be decided jointly between you and your child's therapist and can be modified as needed. A trained therapist who follows a specific treatment protocol will deliver your child's treatment. While each child's treatment is individualized, all treatments are based on specific guidelines from our overall evidence based approach called ACQUIRE Therapy. We believe, based on extensive research and clinical experience, these guidelines help maximize your child's learning potential. We have Occupational Therapists, Occupational Therapy Assistants, and Physical Therapists associated with our clinic. In most cases an Occupational Therapist will deliver your child's treatment, but will be under the supervision and in collaboration with others who have helped develop ACQUIRE Therapy. These include, Dr. Stephanie C. DeLuca, Dr. Sharon L. Ramey, Mary Rebekah Trucks, MS OTR/L, & Dory Wallace, MS OTR/L. All faculty and staff working with you and your child have received special training in the ACQUIRE Therapy process and are regularly monitored by these individuals.

You will be asked to be present and participate in some of the treatment sessions. In addition, both you and your child will be asked to report daily about your child's therapy activities and adjustment to any treatment processes ongoing. You also are encouraged to discuss any concerns that may arise regarding the treatment process. The goal over all therapeutic efforts are to have each child become increasingly capable in play and appropriate daily living skills. We believe that intensive therapy bursts and the evidence based guidelines we follow help to create neuronal connections in the brain and help your child learn the targeted skills.

Principles & Guidelines

We have completed numerous clinical trials investigating intensive neurorehabilitation and believe that intensive individualized bursts of therapy maximize learning by helping children overcome what we have termed developmental disregard. Developmental disregard, briefly defined, indicates that because a specific area of development or developmental process was either not initiated at the appropriate point in development or was altered very early in development (usually because of damage or alterations in the developing brain) children often ‘disregard’ certain movements and or developmental functions. This disregard might manifest in ways that seem as though a child ignores or perhaps is not even aware of the ‘disregarded’ action, process, or movement. We believe and have scientifically investigated certain steps and treatment tools to aid children in overcoming this Developmental Disregard.

For example, the constraint mentioned in ACQUIREc Therapy and I-ACQUIRE is one type of tool to help children with hemiparesis (one side of the body weaker than the other) redirect attention to the weaker side of the body. Delivering therapy hours in intensive treatments bursts so that children receive services many hours a day every weekday for multiple weeks (in comparison to distributed/ traditional models of therapy) is also a tool to maximize learning. An additional tool that is common in all ACQUIRE Therapy models of treatment is based on learning principles used in education and learning environments which says that targeted areas for learning must begin at a child/infant’s current level of function/ability and be progressively shaped in a manner called successive approximation using very small steps and specifically timed positive reinforcement. Our extensive and successful use of these common tools has allowed us to develop additional treatment protocols for children with differing diagnoses and some of those are listed below.

There are numerous therapeutic neurorehabilitation protocols defined under the ACQUIRE Therapy approach. Which protocol your child receives is dependent on your child’s diagnosis, level of impairment, and your treatment goals for your child. We will make recommendations and discuss protocol options with you. Some protocol examples are described below:

ACQUIREc Therapy:

For children with hemiparesis or asymmetry between the abilities of the two sides of their body your child’s intensive burst of treatment may involve constraint of your child’s arm and hand on the side that has more mobility (your child’s more functional arm and hand). The constraint used will be a lightweight cast, specially fitted for your child. The casting procedure is designed to immobilize the functional arm and hand in order to help facilitate use of the involved arm and hand. This intensive treatment is based on previous research surrounding Pediatric Constraint-Induced Movement Therapy (P-CIMT). The ACQUIRE Therapy model began with this form of treatment. While it now extends beyond this single form of therapy, the guidelines (beyond the constraint) were originally developed in clinical trials to inform this treatment approach.

Children are eligible for treatment when the following criteria are met-

- (1) Child has demonstrated significant motor impairment attributable neurological condition which presents with asymmetry between the two sides of the body;
- (2) is between 2 - 21 years of age; and
- (3) does not have any serious complicating conditions or acute medical concerns (seizures must be under control).

I-ACQUIRE Therapy:

Also, based on P-CIMT, this is a P-CIMT protocol aimed at infants under two years of age.

Infants are eligible for treatment when the following criteria are met-

- (1) Infant has demonstrated significant motor impairment attributable neurological condition which presents with asymmetry between the two sides of the body;
- (2) is between 8 - 24 months of age; and

- (3) does not have any serious complicating conditions or acute medical concerns (seizures must be under control).

Whole-Body Intensive Therapy:

This protocol is aimed at helping children who have more global levels of motor impairment gain increased motor function. Successive approximation for motor skills and intensive therapeutic bursts are guiding principles.

Children are eligible for treatment when the following criteria are met-

- (1) Child has demonstrated significant motor impairment attributable neurological condition which presents with motor impairments that may involve all 4 extremities;
- (2) is between 12 months - 21 years of age; and
- (3) does not have any serious complicating conditions or acute medical concerns (seizures must be under control).

Global Developmental Delay Intensive Therapy:

Similar, to the above we have now worked with a variety of children with diagnoses who have delays in development that often include areas beyond just motor skills. It is important to note that we have primarily focused on diagnoses that do manifest in some manner with motor delays or limitations, but we have now successfully used our learning protocols and intensive therapeutic bursts to target other domains of development (e.g., communication, appropriate social skills (reciprocal play), and processing to follow multiple step requests/activities).

Children are eligible for treatment when the following criteria are met-

- (1) Child has demonstrated significant impairments or delays in multiple areas of development attributable neurological condition which presents with some motor challenges;
- (2) is between 12 months- 21 years of age; and
- (3) does not have any serious complicating conditions or acute medical concerns (seizures must be under control).

Risks and Discomforts

We believe and work very hard to minimize all potential risks to your child and family. What those risk and discomforts entail is somewhat dependent on the treatment your child receives. We will discuss your child's treatment activities with you each day and will be in constant evaluation of how we believe your child is responding to our treatment procedures. Please never hesitate to bring up any concerns you might have. We can almost certainly predict that at the start of treatment your child may experience shyness or fear because of interacting with a new therapist, and we predict that your child may show signs of fatigue related to the intensity of the therapy (even though it will be designed to be natural and play-like). We will seek to minimize both of these, but understand that we may need to appropriately push your child's limits in these areas. We will, of course, do this with full transparency with you, making recommendations and listening to any of your concerns.

The most common question about risk and discomfort involves children who receive ACQUIREc Therapy or I-ACQUIRE because it involves the use of a constraint on the child's stronger arm and hand. If your child's less impaired arm is constrained he/she may have a period of adjustment to the restraint. These adjustments may include feelings of anxiety because of the new cast, or frustration in being restrained and prevented from using the more useful arm and hand. We recognize that your child may experience some temporary or brief physical discomfort, including tightness or itching, which is a possibility with any cast. Your child's responses will be monitored daily by project personnel to ensure his/her safety, and you will be encouraged to bring up any concerns or questions you have throughout the treatment period. Based on our previous clinical experience with children from infancy through adolescence, almost all children adjust very quickly and very well to the cast and to the intensive

therapy.

Note: if the cast causes undue distress or discomfort, we can correct this within a very short time (you will be given names and telephones of individuals to contact on a 24-hour basis to ensure that your child will not experience such distress for an extended time period). If this occurs, adaptations to the cast might be made based upon the needs of the child and under the discretion of the supervising therapist. If the cast cannot be modified to ensure the child's safety, a splint will be applied or intensive bilateral activity will be utilized during therapy. In the event of an extreme emergency, you will be allowed to remove the cast by unwrapping the tape which holds the cast together. If this occurs, you agree to contact a project staff member as soon as possible.

Clinical Environment

We provide clinical services based on the evidenced-based practices we have developed through our research experiences via clinical trials. We are not, however a traditional clinic. We are primarily a research facility with a mission to further develop evidenced-based pediatric rehabilitation protocols that can be disseminated to the field to maximize treatments and therapeutic efforts for all children and families impacted by neuromotor impairments. Based on our previous clinical experience, we anticipate that each child will show improvements receiving intensive therapy bursts and we do our best to maximize your child's learning and personal sense of accomplishment during each daily session and the overall treatment process. We cannot, however, make any treatment guarantees. We only seek to provide the best more informed treatment/ therapy that we can for your child, and we will work closely with you to try and maximize your child's potential. Because we are a research facility actively engaged in clinical research efforts we may also ask to use any information collected during your child's treatment for certain purposes, such as in comparison to other children's information, to serve as data for presentations in grants or at professional meetings, or in teaching students. This is not a requirement to receive services, but we want to inform you that we will make the request. We do so because we learn from each and every child, and we want to use what we learn to help more children and families in the future.

Evaluations

Children will be assessed on the first and last day of treatment with various assessments. These assessment sessions will occur at the Fralin Biomedical Research Institute Neuromotor Research Clinic, where a room with video equipment and testing materials are set up. These are primarily observations of play and play-like therapy sessions and assessments. We will, also, interview you about your child's overall well-being and your impressions of any benefits, changes, or negative side-effects of our efforts.

Confidentiality

Your child's health records obtained prior to and during the treatment process will be kept in a secure location at all times. In addition, photographs and videos will be taken during both testing and treatment procedures and are sometimes used in professional presentation without the use of names. If you would rather that your child's pictures or videos not be used, please inform us. Pictures and videos will not be used in any non-professional venues without receiving your expressed consent.

Costs to Participants

The fee for the involved services may be up to a maximum of \$21,000.00. We charge by an hourly rate (\$175.00/per hour). This maximum amount would involve 120 hours combined of testing and treatment. The rate of the therapy process is \$175.00 per hour. Your fee for the services will be based on the number of hours of treatment/therapy your child receives, only. For example, if a child receives 60 hours instead of \$21,000.00, the overall fee would be \$10,500.00. You will receive a weekly invoice based on the number of hours your child receives each week. Because we are not a traditional clinic, we do not have a billing department. We will only request payment from you. Many times, families are able to get reimbursed for the therapy services they receive from our therapists. It is very dependent on an

individual's insurance policy and provider. We can make recommendation about patient insurance advocates that can help your family with that process, upon your requests.

Payment Information

Payment can be made by credit card with the following link:

https://quikpayasp.com/vt/commerce_manager/payer.do?orderType=VTCRINeuromotorResearchClinic

You will receive regular statements. Payment is expected upon receipt of statement.

Privacy Statement: By making this payment via the Virginia Tech payment link, you understand that Personal Identifiers (e.g. name, credit card numbers) will be collected. This information will be used for payment of services you or a family member received at the Fralin Biomedical Research Institute Neuromotor Research Clinic. This information will be used only for the payments outlined in itemized statements provided to you. After payment, credit card information or any other payment related information will not be stored. An updated itemized statement to reflect any payment you have made will be forwarded to you upon receipt of payment. If you wish to make payments via other methods (e.g. personal check or cash), please contact us.

Refund Policy

Amounts due to the FBRI Neuromotor Research Clinic are not eligible for refund since services are complete upon being invoiced.

Cancellation Policy

We require a 60 day notice in the event that you need to reschedule or cancel your treatment session.

Questions

If you have any questions about treatment, you may contact Dr. Stephanie DeLuca at 540-526-2098 or by email at: stephdeluca@vt.edu. For questions related to payments you may contact Laura Bateman at 540-526-2033 or by e-mail at: laurapb2@vt.edu.

By signing below you are expressing your understanding and agreement with the previously stated information and are giving consent for your child to participate in this treatment protocol.

Signature

Date

If you choose to move forward and schedule a time to visit us we will send you additional forms and information regarding housing options (if needed) in the Roanoke area.

Most of All KNOW we wish the best for your child and family. We thank you for your interest in what we do and if visiting us is appropriate for your family, we look forward to helping you maximize your child's development.