**Sit up and Take Notice!**

**A Health & Wellness Project for Infants and Young Children**

**I. Statement of Need**

**A. Needs Statement**

Developmental milestones, which are defined as particular markers of accomplishment and function in the first years of life, are used to assess how the child is doing in relation to established norms. In the gross motor area, developmental milestones include rolling, sitting, crawling, and walking. Not only are these milestones important as individual accomplishments, but they also have an important relationship to one another towards, as Campbell et al1 describe it, “achieving the goals of upright posture, mobility and manipulation – essential elements of environmental mastery and control.” Indeed, there are several excellent websites with information and materials available for both parents and healthcare professionals, such as [www.pathways.org](http://www.pathways.org)2 and [www.beearly.nc.gov](http://www.beearly.nc.gov)3 to help provide information on the approximate ages and stages of typical development as well as identifying further resources if the child is showing signs of developmental delay. Developmental delays may either be the precursor to or an accompaniment of a diagnosis of developmental disability, which is defined by the Center for Disease Control and Prevention (CDC) as “a group of conditions due to a impairment in physical, learning, language, or behavior areas” and it reports that about one out of six children in the United States have one or more developmental disabilities or other developmental delays.4 In the North Carolina Infant Toddler program, eligibility for services for children 0-3 based on developmental delay is defined as: 1) a score that is 2.0 standard deviations below the mean of the composite score on standardized tests in at least one of five developmental areas (cognitive, physical, communication, social-emotional, or adaptive), or 2) a 30% delay on instruments which determine scores in at least one of these developmental area, or 3) a score of 1.5 standard deviations below the mean of the composite score on standardized tests in at least two developmental areas, or 4) a 25% delay on instruments which determine scores in at least two of the above areas of development.5

For some infants and young children with gross motor developmental delays, the development of sitting balance can be difficult. When sitting balance is challenging, this can have a significant effect upon other motor milestones. Although sitting for an adult is usually viewed as a sedentary activity, for the infant or young child having difficulties with acquiring sitting balance this can be a considerable workout. Sitting balance has also been positively correlated with a child’s ability to ambulate.6 For children with significant physical delays or disabilities, therefore, the ability to sit becomes a critical factor for health and wellness and a potential gateway to more advanced motor skills. The focus of this proposal is improving the availability of effective positioning supports in order to help the child with sitting balance development so that they can attain a critical milestone in the development of upright postural control, free up the use of their arms so that they can engage in the manipulative play with toys, and get another step closer to the development of ambulation skills.

Support of infant and toddler development is built upon parent/caregiver education and their willingness to practice and integrate these activities into their child’s daily schedule. Additionally, having access to appropriate services and equipment can be critical in helping the parent/caregiver implement effective home activities to help the child gain more independent gross motor skills.

To address the need for early intervention services of the 0-3 population, the Infant and Toddlers With Disabilities Program (Part C) – part of the Individuals with Disabilities Education Act (IDEA) – was created in 1986 to “enhance the development of infants and toddlers with disabilities, minimize potential developmental delay, and reduce educational costs to our society by minimizing the need for special education services as children with disabilities reach school age.”7 Based on research, it is estimated that 13% of children 0-3 would be eligible for services for this program, but in 2009 only 2.67% of this population were served by Part C early intervention programs nationally, in part due to lack of public awareness.7  In North Carolina, implementation of Part C is coordinated through the North Carolina Infant-Toddler Program (NC ITP), which is a part of the NC Division of Public Health. Eligibility for the NC ITP is based upon developmental delay or and established developmental condition, and services are then orchestrated through 18 CDSAs (Children’s Developmental Services Agencies) throughout the state. The CDSAs work with local service providers to provide services for eligible children 0-3,8 and in 2010 the CDSAs providing services to 5.2% (19,523) of North Carolina’s under three year population.9

For the child with significantly delayed sitting balance, there can be several barriers to addressing their physical management needs in their homes. Suggestions from a study done by Barlett and Fanning on sixty l0 month old babies include consideration of infant equipment to enhance motor abilities for preterm infants.10 A significant barrier can be limited family access to appropriate equipment to support effective home program activities. In addition to therapy services, the CDSA can arrange for assistive technology for durable medical equipment (DME). However, for the majority of these younger children the equipment they could use could be procured at stores providing baby equipment or online. Two examples would be a high-back reclining booster chair, such as the Fisher-Price Space Saver ($48-$53) and Summer Infant Activity Chair ($49), which could be used to position the smaller child upright sitting development while playing with toys placed on the tray; the recliner chair could be tilted back when the child fatigues and the inclined up again when the child is ready for their “sit-up” activity. The assistive technology (AT) provision in the NC ITP policy states that “standard devices, materials and supplies commonly utilized by all infants and toddlers, which are commercially available for purchase by all families, through regular stores and other sources, and which are not specifically designed for children with special needs” are not eligible or considered for AT funding or loan through the Infant-Toddler program.11 The requirement that the family has to purchase these standard types of equipment can therefore be a deterrent to their child progressing; barriers to procuring this equipment can include limited finances, transportation, or motivation.12

The focus of this proposal is to provide timely accessibility and use of effective, commercially available positioning supports - through both equipment provision and parent education – to help young children with delayed sitting balance improve these skills. This equipment can help the child to sit independently with support, with reduction of supports as indicated until the child is able to sit independently without support.13 By achieving this critical milestone, they are developing the upright postural control, freeing up the use of their arms to engage in manipulative play and getting another step closer to developing ambulation skills. In addition to equipment availability, improving sitting balance for the child with sitting delays will also hinge on the parent and/or caregiver’s receptivity, education, and involvement on the use, purpose, and implementation of this positioning activity into the child’s daily schedule.14

**B. Background**

The principles that guide the delivery of early intervention services are key in how the physical therapist fosters progress. Odam and Wolery,15 describe a unified theory of practice in Early Intervention/Early Childhood Special Education (EI/ECSE) that has evidence-based or evidence valued principles, including:

• Families and homes are the primary nurturing contexts

• Strengthening relationships – between parent, child, peers, other caregivers, service provider – is essential

• Children learn through acting on and observing their environment

• Adults mediate children’s experiences to promote learning

• Participation in more developmentally advanced settings is essential – including social and learning opportunities at home and in the community

• EI/ECSE practice is individually and dynamically goal-oriented

For child with significantly limited sitting ability, it is important to develop strategies with the parents and/or caregivers using principles from EI/ECSE to provide opportunities for the child to practice sitting in a nurturing and mediated context. It has been my experience that opportunities for the child to practice upright sitting may be limited due to lack of appropriate positioning equipment. Equipment typically at the home may be a bouncy sling “seat,” boppy cushion, or other equipment that positions the child in a reclined seated position and/or does not provide enough hip and trunk stability to allow practice in a more upright seated position. More supportive commercially available equipment may be suitable, but, as stated previously, the cost can be prohibitive and this equipment is not provided through the NC AT program. It is important to provide the sitting equipment as timely as possible in order to take advantage of the younger child’s neuroplasticity and potential for improvement7 and to model for the parent how effective the use of an appropriate sitting device can be for their child to engage in manipulative play, eye-to eye contact, interaction with siblings and peers, while also working on the upright postural control needed for higher level motor skills.1,6,16 Parent education will also be provided on the importance of providing a variety of positioning opportunities for their child, including floor time activities in supine and prone, activity and duration guidelines, and precautions for sleep positions in prone and in reclined sitting.17,18,19 By having the equipment available to show the parent what their child can do with the appropriate support, working with the parent on how to providing additional positioning if additional adjustments for the child is needed (for example, small towel rolls at the sides of the trunk or hips), and having the equipment immediately available for loan, the probability for daily practice opportunities and child progress improves.13,14

**II. Project Description/Approach**

The goals of the Sit Up and Take Notice program are to develop functional, independent sitting for infants and young children (4-36 months) with significant physical delay and/or disability by:

1) Education of CDSA staff and providers and Family Support Network Staff of the relevance and implementation strategies of the Sit Up and Take Notice Program, as measured by a pre and post test at the beginning and end of a one-hour inservice training, with post test scores at 90% for all participants.

2) Improving family access to therapeutic commercially available equipment so that it is easily and readily available to support gross motor skill development, specifically for the facilitating of active sitting balance. Within 14 days of enrollment into the Sit Up and Take Notice Program, 95% of the families enrolled in this program will have seating equipment appropriate for their child’s active sitting balance development.

3) Improve parent and caregiver understanding of the relevance of active sitting opportunities for their child, as measured by parent questionnaire and/or interview at enrollment and at 6 month intervals or at the conclusion of services if earlier, with at least 90% of participants will showing increased understanding.

4) Incorporating active, upright sitting opportunities into the child’s daily positioning and activity regimen. Within 30 days of program enrollment, 95% of the families will be able to provide opportunities for active sitting with age-appropriate activities for a minimum of three 30 minute periods daily, as measured through weekly documentation of the child’s daily positioning/activity schedule by the parent or caregiver.

5) 90% of the children enrolled in the Sit Up and Take Notice program will improve their gross motor function scores by at least l0%, as measured by either the AIMS (for children under 18 months), or by the PDMS-2 (for children over 18 months of age), within a 6 month period.

The target population for this project will be children that have qualified and are receiving services through the Greensboro CDSA, which serves the Guilford County area. This project will have five components: 1) Inservice training for the Greensboro CDSA staff and providers and Family Support Network staff, 2) child identification based on assessment information, including a baseline of their current activity schedule, 3) equipment procurement, 4) parent education and collaboration on daily positioning and practice implementation, and 5) program promotion in conjunction with the Greensboro CDSA and the Family Support Network of Central Carolina.20

The first component of this project will be to provide a one hour inservice training to the Greensboro CDSA staff and related service providers and the Family Support Network staff. The inservice training will highlight the development of active sitting, the importance of practice opportunities, the identification and use of equipment to support this activity when indicated, parent education and problem-solving strategies to incorporate appropriate activities into the child’s daily schedule, and the methodology to obtain, use, and return any needed commercially available equipment for seating as indicated. A pre- and post-test will be given to the participants to measure staff and provider understanding.

The second component will be to identify those children who will benefit from these interventions. In full term infants, the typical age for propped sitting is 5-6 months; floor sitting with full trunk extension and high guard positioning of the arms is 5-7 months and independent sitting with secondary curves is 7-9 months.21 Therefore, the age range for this project will be from 4 months to 36 months. The 36 month limit was chosen as more customized equipment (DME) is usually indicated for the older, larger child to address their sitting support and balance dysfunction; this is also the age limit for services through the CDSA program. Children can be identified for service based on a GMFCS – E & R (Gross Motor Function Classification System – Expanded and Revised) Levels III-IV for those under two years old, and Levels II-V for ages over 2 years old. Children from 4-18 months can be can assessed with the AIMS (Alberta Infant Motor Scale); children over 18 months can be scored using the gross motor quotient of the PDMS-2 (Peabody Developmental Motor Scale – 2nd ed), both initially and at 6 month intervals and/or upon discharge from CDSA services.22 A parent questionnaire and/or interview will be provided, asking about the typical positioning and activity schedule for their child, including the types of equipment that are currently, how often the child is held, and current beliefs, understanding, and expectations about their child’s sitting development and overall development.

The third component will be the timely procurement of commercially available seating positioning equipment, if indicated, either as a part of the assessment proceedings or within 1 week of the initial assessment. Demonstration of the child practicing active, upright sitting activities in appropriate equipment will be assessed and demonstrated by the provider in collaboration with the parent, and a daily guideline for home positioning and activities subsequently developed, with loan of the equipment for use by the child if appropriate. An example might be that active sitting is addressed in a high back high chair with towel rolls providing additional side support during mealtimes, and the child’s sitting position supported in the stroller so he is able to sit in better alignment for the parent’s afternoon walk. Commercially available equipment does not have to be limited to addressing active sitting, but this component needs to be included. Commercially available equipment seating equipment can address chair sitting (ex: Fisher-Price SpaceSaver chair, Summer Infant Seat, Children’s Factory Cubed chair), recreational sitting (small rocking or riding toys), and strollers could also be considered. Note: if a child cannot be supported by anything other than DME (Durable Medical Equipment), that family would be able to access equipment through AT loan, Medicaid and/or insurance. A literature review of specific commercial available positioning equipment did not reveal any results other than the recommendation by Barlett and Fanning for “infant equipment;”10 another potential offshoot of this project could be a guideline for commercially available positioning equipment for infants and young children with developmental delays, which could be made available through the CDSA, Family Support Network, and the Pediatric Section of the APTA.

The fourth component, parent education, is occurring as a part the previous two components. Dusing et al23 define parent education intervention as a way “in which the parent is taught specific ways they can provide intervention to their infant as part of caregiving or in addition to caregiving,” and that the first choice of educational methods in their pilot study was observation of the child’s assessment while the PT described the assessment and made recommendations about play activities; the least preferred method was through a brochure.Based upon the parent questionnaire and/or interview, education can be tailored for the family, with the collaborative goal of having a variety of positioning and activity goals throughout the day which will also include opportunities for active sitting development. This questionnaire or interview will also be done every 6 months or at the conclusion of services.

**III. Evaluation**

The purpose of the Sit Up and Take Notice wellness program is to improve parent and provider education and the availability and utilization of commercially available equipment in order to support and assist the at risk infant or young child attain the critical developmental milestone of sitting. As the child gains the postural control needed for sitting, this in turn helps set the stage for higher level motor activities. The effectiveness of this program can be assessed through the collective information and data obtained from each of the program goals. For the first goal addressing staff and provider education, the pre- and post tests before and after inservice training can ensure that knowledge levels will support program goals and implementation. The second goal, which relates to the expedient access to therapeutic commercially available equipment, can be measured by looking at enrollment dates and, if the need for equipment was indicated, the date this equipment was provided to the family. Parent and caregiver knowledge of the relevance and integration of regular active sitting activities for their child, which is the third goal, can be assessed through the parent questionnaires and/or interviews at enrollment, at 6 month intervals, and at the conclusion of services. The fourth goal, measuring the daily implementation of active, therapeutic sitting opportunities for the child, can be by done by looking at the weekly schedule checklist completed by the parent or caregiver, which will indicate the frequency, duration and tolerance to the activity. Documentation of the child’s progress in sitting will be assessed by the PT providers through the AIMS or PDMS-2 measures at program entry, 6 month intervals, and at program exit. Additional outcome evaluation will be obtained through use of a parent questionnaire at program exit to measure satisfaction level with the program and suggestions for improvement, and questionnaires completed by the providers every 6 months to gain their input on the program’s effectiveness and utility and recommendations for improvement.

In order to provide continued education and resource availability of commercial available positioning equipment, the final component of this program would be to develop the ongoing establishment of a voucher program that allows the pediatric physical therapy service provider to purchase the seating related equipment needed for the child based on assessment information. Consideration of the purchase of equipment through children’s consignment stores could also be considered as a cost savings measure. This program could be coordinated through the Family Support Network of Central Carolina, and could hopefully grow to be offered statewide. In this way, the Sit Up and Take Notice program can assist many families help their infant or young child with motor delays to gain meaningful and functional progress.

**References:**

1. Campbell S, Palisano R, Orlin M. Physical Therapy for Children, 4th ed , Elsevier Saunders. St. Louis. 2012:54.

2. Pathways.org Baby Milestones. <http://pathways.org/awareness/parents/new-parents/>. Accessed online October 13, 2012.

3. NC Infant Toddler Program Milestones Chart. <http://www.beearly.nc.gov/data/files/pdf/milestones.pdf>. Accessed online October 13, 2012.

4. CDC. Developmental Disabilities. <http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>. Accessed online November 17, 2012.

5. NC Early Intervention Branch, Division of Public Health, NC Department of Human Services. New Eligibility Definition for the NC Infant Toddler Program (effective 7/1/2006). <http://www.beearly.nc.gov/data/files/pdf/EligibilityDefn.pdf>. Accessed online November 17, 2012.

6.Montgomery P. Predicting Potential for Ambulation in Children with Cerebral Palsy. Pediatric Physical Therapy 1998; (10): 148-155.

7. The Importance of Early Intervention for Infants and Toddlers with Disabilities and their Families. The National Early Childhood Technical Assistance Center. [www.nectac.org](http://www.nectac.org). Updated July 2011. Accessed September 15, 2012

8. North Carolina Infant-Toddler Program (NC ITP). www.beearly.nc.gov. Updated August 29, 2012.Accessed September 15, 2012

9. NC Early Intervention Branch, Division of Public Health, NC Department of Human Services. *Early Intervention At-A-Glance*. <http://www.beearly.nc.gov/data/files/pdf/EIatAGlance2010.pdf>. (2010). Accessed online October 13, 2012.

10. Bartlett D, Fanning J. Relationships of Equipment Use and Play Positions to Motor Development at Eight Months Corrected Age of Infants Born Preterm. *Pediatric Physical Therapy.* 2003: 8-15. DOI: 10.1097/01.PEP.0000051693.49199.41. Accessed online November 18, 2012.

11. North Carolina Infant-Toddler Program Policy Bulletin #27, Item #7, p. 27-4. <http://www.beearly.nc.gov/data/files/pdf/infanttoddlermanual/Bulletin27.pdf>. Updated 1/1/12. Accessed September 15, 2012.

12. McPhillips M, Jordan-Black J. The effect of a social disadvantage on motor development in young children: A comparative study. *Journal of Child Psychology and Psychiatry*. 2007; 48: 1214-1222.

13. Butler P, A preliminary report on the effectiveness of trunk targeting in achieving independent sitting balance in children with cerebral palsy. *Clinical Rehabilitation*. 1998; 12: 281-293.

14. Bartlett D, Fanning J. Relationships of Equipment Use and Play Positions to Motor Development at Eight Months Corrected Age of Infants Born Preterm. *Pediatric Physical Therapy*. 2003; 15:8-15

15. Odom s, Wolery M. A Unified Theory of Practice in Early Intervention/Early Childhood Special Education: Evidence-Based Practices. *Journal of Special Education.* 2003; (37): 164-173

16. Rochat P, Goubet N. Development of Sitting and Reaching in 5- to 6-Month-Old Infants. *Infant Behavior and Development*. 1995; (18):53-68.

17. Dudek-Shriber L, Zelazny S. The effects of prone positioning on the quality and acquisition of developmental milestones in four-month-old infants. Pediatric Physical Therapy [serial online]. March 2007;19(1):48-55.

18. Côté, A., Bairam, A., Deschenes, M., & Hatzakis, G. (2008). Sudden infant deaths in sitting devices. Archives Of Disease In Childhood, 93(5), 384-389.

19. Callahan C, Sisler C. Use of seating devices in infants too young to sit. *Arch Pediatr Adolesc Med*. 1997; 151(3):769-771.

20. Family Support Network. <http://www.fsncc.org>. Accessed online on November 18, 2012.

21. Tecklin J. Pediatric Physical Therapy, 4th ed. Lippincott Williams & Wilkins. Philadelphia. 2008:19.

22. Campbell S, Palisano R, Orlin M. Physical Therapy for Children, 4th ed , Elsevier Saunders. St. Louis. 2012:70-72.

23. Dusing S, Muray T, Stern M. Parent preferences for motor development education in the neonatal intensive care unit. *Pediatric Physical Therapy*. 2008; 20: 363- 386.