Eastern North Carolina (ENC) encompasses a large geographic area population without a regional pediatric seating and equipment clinic (PSEC) to service children with disabilities (CWD). Many children with disabilities (CWD) in Eastern North Carolina are unable to receive pediatric specialized adapted seating and seated mobility services. The majority of CWD in ENC receive seating and equipment evaluation and prescription through local clinicians who do not have specialized assistive technology (AT) education or training. Families who want specialized services are forced to travel 100 miles or more to the closest pediatric seating clinic, in Chapel Hill, NC, Durham, NC or Norfolk, Virginia. The aim of this proposal is to describe and justify the need for an ENC pediatric seating and equipment clinic.

Statement of Need

Eastern North Carolina Children with Disabilities

Eastern North Carolina is comprised of more than 40 primarily rural counties with a continually expanding population of more than 1,000,000 people.¹ As in other rural areas, families in ENC have limited access to specialized health care services.^{2,3} The primary patient population for the ENC PSEC draws from counties adjacent to Pitt County and counties to the east, northeast and southeast. (See Figure 1) The far northeast portion of ENC is located within a reasonable driving distance to The Children's Hospital of the King's Daughters' pediatric seating clinic and therefore is not included within the potential service area. The average distance to travel from identified counties to ENC PSEC is 46 miles. Approximately 1956 children with special health care needs live within the delineated service area. (See Table 1) However, this estimate is based on general North Carolina survey data and the actual numbers are potentially higher. Another source, The American Community Survey estimates 6.3% of school-aged children living outside of metropolitan areas report vision, hearing, cognitive or ambulatory difficulties; .75% and 1% report ambulatory or ADL difficulties respectively. Based on these statistics and the population of children ages 0-17 in the area served, the estimate of potential clients for an ENC PSEC may be closer to 2100-3000.⁴



Figure 1.* Map of ENC PSEC Geographic Service Area

*County Map Modified from NC State University State Maps⁵

ENC	Distance from	Population ^b	% of Population	Calculated]	
County	ECU Allied		0-17 years of	Population		
	Health Campus ^a		Age ^b	Children Ages 0-		
				17		
Pitt County	2	174,263	22	38,337		
Bertie	50	20,344	19.3	3,926		
Beaufort	24	47,464	21.2	21,232		
Carteret	85	68,434	18.6	12,700		
Craven	47	104,489	22.7	23,700		
Duplin	63	60,084	25	15,000		
Edgecombe	35	55,574	23.5	13,000		
Greene	21	21,232	21.9	4,649		
Jones	47	10,215	19.6	1,900		
Lenoir	29	57,961	25.6	14,800		
Martin	30	23,669	20.8	4,923		
Nash	51	95,840	22.9	21,947		
Onslow	71	190,000	26	49,400		
Pamlico	57	12,953	16.7	3,367		
Pender	89	55,334	22.4	12,394		
Wayne	43	124,583	24.2	30,149		
Wilson	34	81,667	23.8	19,400	Estimate of	Estimate of CSHCN in ENC
					CSHCN in ENC	reporting functional limitations
					(3.9%) ^c	requiring DME in last 12 months
						(18%) ^c
Total:						
		1,204,106		278,760	10,871	1,956

a Mapquest Directions based on Distance from County Courthouse to proposed location of ENC PSEC.⁶ b Taken from 2013 Census Bureau Data⁷

c Based on data from 2009/2010 National Survey of Children with Special Health Care Needs for North Carolina ^{8,9}

Background Information

Wheelchair and adapted seating assessments are within the scope of practice for physical and occupational therapists. Entry-level PT curriculum lays the foundation for pediatric seating and equipment assessment based on basic biomechanical principles, evaluation components, and clinical reasoning skills. However, typical PT programs only offer 0-8 hours of basic wheelchair and seating assessment education within patient care, adult neurology, or pediatric laboratories or classroom instruction. ¹⁰ Entry level education does not ensure competency in adapted seating, wheeled mobility or equipment assessment and prescription. ^{10,11} The creation of a special interest group within the Neurology Section of the APTA recognizes the specific knowledge base necessary for assistive technology in seating and mobility. ¹⁰ Lack of clinician experience, education and training results in PT's over-reliance on assistive technology professionals and vendors to assist with clinical decision-making for equipment choice and specific set up. This practice potentially creates a conflict of interest due to financial gain for equipment providers based on manufacturer incentives and/or contracts, as well as a pushing therapists and patients towards more expensive equipment. ¹¹

Many hospital systems throughout NC, including Vidant Medical Center offer adult seating clinics focusing primarily on wheeled power and manual mobility. Children and their families from ENC

may choose to attend local primarily adult seating clinic or travel to UNC-CH or Duke Hospital Systems to receive equipment evaluations through diagnosis specific outpatient clinics or pediatric outpatient services. However these systems do not offer a PSEC dedicated to the needs of children, and patients often have long waiting periods for initial appointments.^{12,13} Some children with complex medical diagnoses, especially those with respiratory dysfunction requiring ventilation, cannot tolerate extended travel. The financial impact of extended travel poses an additional barrier. Many families cannot afford loss of income/cost of gas travel for equipment assessment and intervention. Local clinics employ capable and experienced pediatric clinicians but rely on vendors for all equipment trials. Currently, the closest specialty PSEC is more than 100 miles from Greenville, NC and offered by The Children's Hospital of the King's Daughters in Norfolk, Virginia.¹⁴ At King's Daughters clinicians with significant experience and education in pediatrics and assistive technology perform thorough equipment evaluations, training and follow-up. For families in ENC who cannot or will not travel, local outpatient therapists evaluate and prescribe expensive, customized equipment without extensive pediatric equipment education, training or equipment trials. Guerette et al. surveyed clinicians in the United States prescribing power mobility for young children and found that 40% lack extended loaner access for trial equipment.¹⁵ Additionally, 62% of those who lacked adequate access for loaner wheelchairs reported this as a negative impact on appropriate equipment prescription.¹⁵ This practice potentially results in suboptimal assistive technology provision with negative impacts on patient comfort and function, which may lead to unnecessary secondary complications.¹⁰

The evidence supporting the role of specialized seating and equipment clinics is based primarily on expert opinion, accepted clinical practice guidelines, and qualitative or descriptive research studies. ^{2,16-21} A few studies report improved outcomes after assessment and intervention provided by trained equipment clinicians for the elderly or for adults s/p spinal cord injury.^{16,17,19} Kennedy et al. found that patient receiving early education along with a specialized seating assessment were more independent with self-management of pressure relief than those with a delayed assessment.¹⁷ Hoenig et al. reported that elderly patients receiving referrals for a specialized seating assessment were more likely to use wheeled mobility and modify homes for wheeled access.¹⁶ No studies are available comparing pediatric outcomes performed by a pediatric specialized clinic versus the treating therapists. However, children with significant physical disabilities often require maximal postural supports with or without high tech assistive technology. Optimally prescribed pediatric assistive technology from a trained professional potentially greatly impacts child development, posture, function, participation, and quality of life for children and their families with significant physical disabilities.²²⁻³² Comprehensive equipment assessments are time-consuming and individualized.^{18,20,21,33} According to Isaacson, expert clinicians in the US perceive time constraints, reduced reimbursement, lack of equipment for trials, and difficulty with home environment assessment to be barriers to best practice in seating and equipment assessments.²¹ Wright et al. proposes the possibility of therapist bias as a contributing factor for omitted essential components within the evaluation process because of familiarity with children prior to a seating assessment.¹⁸ All of the above outlined barriers, constraints and bias are mitigated with the establishment of a service oriented ENC PSEC.

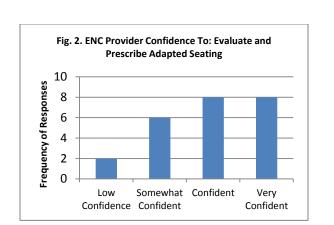
Results of ENC Provider Survey

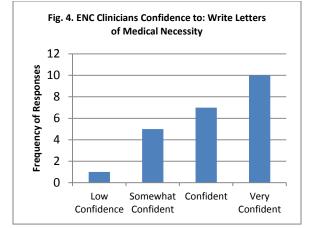
Table 2. Description of Respondents

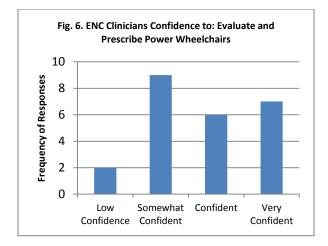
Physical Therapist	18
Occupational Therapist	1
Assistive Technology Professional	2
Physician	1
Physical Therapy Assistant	1
Unknown	2
Total	24

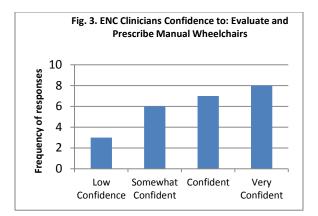
A survey was emailed via Survey Monkey to target pediatric physical therapists in ENC, Coastal Pines District of the NCPTA, local physicians, and assistive technology professionals (ATPs) to investigate the need for and likelihood of referral to a PSEC. The survey also assessed self-reports of clinician confidence in assessing, prescribing and documenting pediatric seating and equipment. (See Figures 2-6) Twenty-four responses were collected as described in Table 2. The total number of surveys requested is unknown. Of the 24 respondents, 86% were physical therapists/physical therapy

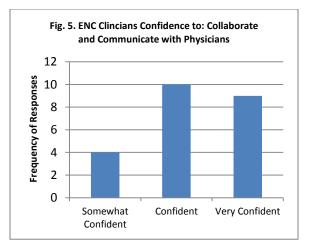
assistants and 10% were ATPs. Most respondents worked with children in outpatient centers or the school system. The survey indicated a positive response to a PSEC with 62% (15/24) in favor of referring patients to an ENC PSEC. Even though the majority of respondents were confident in their abilities to fulfill equipment needs of CWD in ENC the results indicate a positive likelihood of referral to a PSEC. This may be due to decreased productivity, reimbursement and/or reported overconfidence in their abilities. Respondents to the ENC survey reported the lowest confidence with pediatric power mobility, with 11 out of 24 reporting "low confidence" or "somewhat confident". Low clinician confidence in AT prescription has been reported Long and Perry; who found that pediatric physical therapists in the US lacked confidence on 10 out of 11 components of an AT evaluation, prescription and treatment. ¹¹ The authors found 87% of respondents lack confidence with high tech assistive devices including power wheelchairs.¹¹ In the subgroup of physical therapists working more often with AT, confidence with AT was much higher ("high tech" 26% confident, "matching device with a need" 36% confident) but therapists still indicated significant lack of confidence. Therefore, ENC respondents may have overestimated their confidence due to lack of training, overreliance on vendors/ATPs and threat of revenue loss related to referring patients to a seating clinic. One clinician expressed concern that an ECU sponsored ENC PSEC would interfere with private practice. However the mission of an ENC PSEC will be to support local therapists, DPT students, and children/families by providing access to extended loaner equipment, a variety of input devices, and postural supports from a clinician with specialized equipment training. Referral to the ENC PSEC would be unnecessary for children receiving appropriate equipment prescription via previously established relationships with local therapists unless additional support or high tech equipment is needed. This misperception will be rectified through presentations to PTs in local school systems, outpatient clinics, hospitals as well as physicians to explain the mission, role and aim of an ENC PSEC. Although ENC providers reported confidence in their abilities to assess, prescribe and document equipment needs for CWD this did not greatly impact their likelihood to refer to a local PSEC. A favorable desire to refer may be due to reduced productivity and increased time spent on lengthy paperwork and communication with vendors and physicians. The results might also reflect a favorable response from PTs working in the schools. School PTs only prescribe equipment that is primarily for education purposes and outpatient health care providers meet home needs.











Mission/Role of ENC PSEC

The ENC PSEC will:

- 1. Provide specialized and individualized seating and equipment evaluation, prescription and training for ENC children with disabilities and their families.
- 1. Educate and train ECU DPT students on best practice standards including the necessary components of equipment evaluation, prescription and intervention.
- 2. Provide access to pediatric equipment, especially high tech power mobility drive controls, for ENC children with disabilities and local pediatric therapists.

Location, Staffing and Equipment

The ENC PSEC will be located in the East Carolina University Department of Physical Therapy laboratories. Services will be offered once a week with an emphasis on power mobility assessment and training. Patients and physicians will schedule appointments through the scheduler currently responsible for the ECU PT clinic. ECU faculty member, Christine Lysaght, PT will be responsible for patient assessment, equipment recommendations, and all necessary paperwork. Multiple relationships with a variety of companies were established during attendance at the International Seating Symposium, in Nashville, TN on February 25-18th, 2015. Permobil has offered demo power wheelchairs in addition to a variety of input controls to use in the ENC PSEC. Easy access to a variety of drive controls will allow for extended practice and training with different drive controls in a safe and open clinic environment. Additional companies such as Ti-Lite, Quantum, Sunrise, Convaid, Rifton, Ki Mobility and Ottobock will support the creation of an ENC PSEC. These companies will provide the ENC PSEC equipment to keep on site for trials based on demand.

PSEC Procedures

Seating and equipment evaluation and delivery process will take place over a minimum of three visits. ²⁰ Children and families from ENC will be referred by pediatricians, pediatric neurologists, pediatric physical medicine and rehabilitation physicians, or treating therapists. Self-referrals will also be accepted. Although PTs in NC have direct access, third party payers require physician's signature to certify medical need for equipment. Therefore, prior to equipment trial on the second visit a physician's prescription is required for all patients submitting to Medicaid or insurance company for funding. A thorough physical therapy evaluation will be completed to determine the desired equipment to trial based on child's body structure/function impairments, environmental considerations, and elicited child/family equipment goals. The family chooses their preferred ATP from a list of area equipment companies. The appropriate vendor/ATP performs the home assessment and once completed a collaborative second clinic visit is scheduled with the patient/family, ATP and PT. The purpose of the second clinic appointment is to provide the child and family opportunities to try potential equipment options, discuss funding and educate the family on safe and effective equipment. Once optimal equipment

is chosen, the vendor completes the necessary order forms and the PT composes the letter of medical necessity (LMN), which is then sent to the ordering physician for signature. After the LMN is signed by the physician the ATP submits to the third party payer for approval. After receipt of funding approval the ATP orders the approved equipment and contacts the PSEC to schedule the patient for equipment check out.

Additional Visits for Power Mobility

Young children or children with multiple disabilities may need additional visits to accurately assess readiness for and appropriateness of power mobility. ^{11,24,34,35} Early power mobility has been shown to enhance development, function and quality of life. ^{25,32,34-38} Guerette et al. found 3 years of age to be the youngest average of children recommended for power mobility providers and clinicians. ¹⁵ Timely access to power mobility is also impacted by lengthy approval and possible denials from insurance companies delaying delivery up to one year after evaluation. ²⁵ Although no objective data exists, the clinical experience of the author suggests that most children in ENC are not evaluated for or prescribed power mobility until they reach school age. Early intervention services provided by physical therapists are too often focused on gross motor development versus participation and environmental access to toys, peers, family and objects. ³⁹ Early access to power mobility, even for children who may eventually progress to independent mobility without an assistive device, is supported to improve cognition through early perceptual motor activities. ^{31,32,39} However, the results of the ENC survey indicate lower clinician confidence with power mobility compared to other lower technology equipment. An ENC PSEC will provide a valuable and necessary service to assess and train young children with multiple disabilities for power mobility.

Budget/ Billing and Potential Reimbursement PSEC Services

The only expenses associated with an ENC PSEC at ECU are physical therapist compensation, billing, one-time \$500 cost of ATP certification, ATP certification renewal, and Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) membership.⁴⁰ The PSEC will be an additional service offered by the ECU PT clinic. There is no extra equipment or support staff required. Patient scheduling, billing and physical space are furnished by ECU. The billing department collects 7% of billed revenue from the PT department for their services. The largest PSEC expense is \$45 per hour PT compensation, based on negotiated salary and benefits.

Visit	CPT Codes	PT Time	Units Billed	Reimbursement Rate	Total Potential
		Block		Medicare/Medicaid per	Reimbursement
				unit*	
Initial	97001	1.5 hours	Untimed	\$72.93	\$132.25
	97542		2 units	\$29.66	
Second	97542	1.5 hours	6	\$29.66	\$177.96
Follow Up	97542	30 minutes	2	\$29.66	\$59.32
				Total Revenue per patient	\$369.53
				PT Compensation per	\$157.75
				patient	
				Profit per patient	\$211.77
				100 Patients per year	\$21,177
				ECU billing charges 7%	\$1482.39
				ATP Re-	\$225.00
				Certification/RESNA	
				Membership	
				Total Potential Profit	\$19469.61

Table 3. Potential Yearly Costs and Revenue from ECU sponsored ENC PSEC

*Reimbursement per unit based on estimate from APTA's Multiple Procedure Payment Reduction (MPPR) Calculator⁴¹ actual reimbursement may be vary

Entry-Level Physical Therapy Education

The ENC PSEC will allow increased exposure and education on assistive technology for physical therapy students. The PSEC will be housed in the ECU DPT academic building thereby providing students access to pediatric equipment, exposure to collaborative practice and clinical experience with evaluations. ECU PT students will take part in assessments during pediatric or neurologic rehabilitation coursework in the fall, spring and summer semesters of their second year. Relationships built with ATPs, vendors and patients provide a resource for assistive technology education within the curriculum. The long-term plan is to leverage the experience and education gained through the PSEC to create an interdisciplinary assistive technology seminar course available to ECU physical, occupational and speech therapy students. A seminar course for students interested in learning more about assistive technology for individuals with disabilities and incorporation of the PSEC into entry-level education provides an avenue to advance clinical judgment and skills.¹¹ An interdisciplinary AT course will serve the mission of both ECU and The College of Allied Health Sciences to advance student knowledge and experience through innovative and clinically relevant learning opportunities.^{42,43}

Potential Future Research Agenda

An ECU-sponsored ENC PSEC also provides an avenue for future clinical research for students and faculty interested in the field of assistive technology. The medical community and families accept pediatric equipment for children with limited functional abilities to improve function and participation but this theoretical construct lacks strong supporting evidence.^{27,28,44,45} Present day healthcare systems demand evidence supporting therapeutic interventions and often deny medically necessary equipment citing lack of evidence. For example, Medicaid across the country is denying standers for children with disabilities claiming lack of evidence.^{46,47} One barrier to clinical studies is a lack of reliable, valid and clinically useful pediatric outcome measures specific to assistive technology. Future research opportunities include clinical studies supporting equipment use to improve function and participation, and outcome studies assessing the reliability and validity of adult adapted seating measures in the pediatric population or the positive effects of adapted standing.

Evaluation of PSEC Services and Equipment Outcomes

Evaluation of services provided by the ENC PSEC comprises of two distinct components,

- 1. Patient/family satisfaction with assistive technology assessment and provision,
- 2. Body Structure function, activity and participation outcomes related to equipment assessment and intervention.

Both qualitative and quantitative data will be collected at the initial visit, completion of the second visit and 6 months later via phone or digital survey. (See Table 4) During the initial evaluation photographs will be taken in current adapted seating, wheeled mobility or supported sitting. For example, children typically arrive to clinics in non-adapted strollers (umbrella or similar), carried by family or in current seating system. For children not currently using adapted seating or standing equipment, photographs in supported positions will be taken. Specific outcomes measures will differ among patients but may include the Wheelchair Outcome Measure (WhOM)^{48,49}, Kwaliteit van Zorg'; Quality of Care Scale (KWAZO)^{50,51}, Family Impact of Assistive Technology Scale for Adaptive Seating (FIAST-AS)^{28,52-54} and additional questions regarding frequency of use, functional use and participation.

Outcome Measure	Initial Evaluation	Follow-up	6 months after	
		(Equipment	Equipment	
		Delivery)	Delivery	
Photographs	Х	Х		
WhOM	Х		Х	
KWAZO		Х		
FIAST-AS	Х		Х	
Additional	Х		Х	
Questions				

Table 4. Possible Outcome Measures and Time of Use

The WhOM elicits individualized patient/family participation goals and rates the importance and performance satisfaction both at assessment and 6 month follow-up after equipment provision.⁴⁸ The WhOM is a reliable and valid measure of self-report wheelchair comfort, skin breakdown and participation for adults with SCI.⁴⁹ The WhOM has not been studied in children but is very similar to the Goal Attainment Scale, a reliable and valid measure of functional goal achievement for children with disabilities.⁵⁵

The KWAZO is a valid and reliable measure of assistive technology delivery service for adults and parents of children with disabilities. ^{50,56} This scale, originally developed in the Netherlands, is a quick

seven question survey that rates patient satisfaction with assistive technology services on a 3 point Likert scale.^{50,56} (See Appendix A)

The Family Impact of Assistive Technology Scale for Adaptive Seating (FIATS-AS) is a parental response report designed to assess the impact of adaptive equipment provision on the function, participation and quality of life for children and their families. ^{28,53} The FIATS-AS consists of 64 questions from nine categories; child autonomy, caregiver relief, child contentment, doing activities, parent effort, family and social interaction, caregiver supervision, safety and technology acceptance. ²⁸ The FIAST-AS demonstrates good validity and reliability. ^{52,54} The FIAST-AS has been used to document significant improvement after adapted seating intervention for young children with disabilities. ⁵³

Lastly, frequency of use of equipment or assistive technology is another necessary outcome measure. Five additional questions will be used to collect information on AT use, abandonment and perception of needs met.⁵⁷ (See Appendix B)

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Appendix A.

KWAZO*

Please answer each question as:	Insufficient	Sufficient	Good
1. Could you always reach the service delivery professionals			
easily?			
2. How clear was the information about the equipment			
application and the possible solutions that the service delivery			
professionals gave you?			
3. How well was the cooperation and the communication			
between different service delivery professionals? (ex therapist,			
equipment company, physician)			
4. Did the service delivery professionals have sufficient know			
how? (expertise)			
5. Was your application (equipment request/order) handled			
quickly?			
6. Were your own opinion and wishes considered in choosing an			
assistive device?			
7. Was the use of the assistive device well-explained to you?			

*Taken from Dijicks et al. (2006)⁵⁰

Appendix B.

Additional Questions*

1. Age:

- 2. Patient Male or Female:
- 3. Does your child currently use any equipment or assistive technology in the home?

Yes: Please list

a._____b.____c.___d.____e.____

No

4. How often does your child use each of above listed equipment?

	More than once a day	Once a day	2-3x a week	2-4x a month	Not at all
a.					
b.					
С.					
d.					
е.					

5. Did the equipment your child received from our equipment clinic meet your expectations?

Met Completely Met Very Much Met Somewhat Met Very Little Not at all
--

OR

N/A This is our initial evaluation.

*Adapted from Samuelsson and Wressle. (2008) 57