

Can evidence based recommendations be made for the use of assistive technology to
increase the participation of infants and toddlers with disabilities?

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Abstract.

Can evidence based recommendations be made for the use of assistive technology to increase the participation of infants and toddlers with disabilities?

Over the past 25 years the field of Assistive Technology (AT) has continued to grow as the demands of society push forward the boundaries of rehabilitation science and technology. AT has been recommended as an intervention for improving the functional capacity and participation of infants and toddlers. But are these recommendations based on empirical evidence? This paper describes the levels of evidence used to assess current research, and investigates the type and quality of peer reviewed research publications, through examples of clinical evidence based questions investigating, positioning, mobility, AAC, environmental control, and switch interface devices with infants and toddlers.

The research available is comprised of studies of varying levels of evidence and studies that are not empirical in nature. Many of these studies are of lower quality with limited numbers of participants or lacking the randomization and control needed for ranking at a higher level of evidence.

The author concludes that for practitioners working with infants and toddlers with disabilities, the use of assistive technology should be considered, but clear and consistent evidence to support the selection, implementation, evaluation and expected prognosis for infants and toddlers is not yet available. Recommendations are made to include AT in an interdisciplinary research agenda.

Key words: Assistive technology, young children, infants and toddlers.

Introduction

An assistive technology device is often defined as “ Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a individuals with disabilities “ (Technology related Assistance for Individuals with Disabilities Act, 1999). This broad definition includes devices and equipment to support a child’s function across many domains of development. The rapid evolution of technology and the integration of technology into everyday routines of families have lead to more and more devices becoming available for the young child. Infant seats, swings, and button activated toys are now seen in everyday life of many infants and young children. With minor adaptations these readily available devices can be adapted for use by infants and toddlers with disabilities. In some instances specially designed devices are prescribed to meet specific functional needs of children with disabilities.

The use of AT with infants and toddlers is widely recommended, (NECTAC, 2009; Sooner start, 2009, National Center to Improve Practice (NCIP), 1998). However the utilization of AT with infants and toddlers who are participating in early intervention remains limited (Campbell, Milbourne & Wilcox, 2006). In 2003 only 7% of children receiving early intervention services were also receiving AT (Long, Huang, Woodbridge, Woolverton & Minkel, 2003).

Making evidence based recommendations requires, access to high quality research, critical appraisal, formulation of a clinical question, and the ability to analyze the information in the context of individual circumstances (Dawes et al, 2005). Rehabilitation professionals collect, analyze and integrate information from research and individual assessments to make

evidence based decisions. But: is there sufficient high quality research to guide the selection, implementation and evaluation process in AT? And are rehabilitation professionals sufficiently trained to be able to make evidence based recommendations?

Discussion

To answer these questions we first need to clarify what constitutes high quality empirical evidence. What is the “gold standard” for showing causality of results?

There are several different systems in the literature that are used to grade research and to assign a “level of evidence”. Sackett (2000), and the Center for Evidence Based Medicine (CEBM) (2001), are examples of similar classification systems. The American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD) published a grading system in 2004. The AACPDMD system is based on the work of Sackett and includes single subject research designs (SSRD). In this system level 1 indicates the highest level of evidence representing a strong inference of causality. At each preceding level the likelihood that the intervention was the cause of the outcomes decreases, with level V only hinting at the possibility of causality (AACPDMD, 2004).

The task of methodically finding and grading the evidence related to a specific clinical question may be daunting for the rehabilitation professional working in a clinical setting. However, a useful tool for the practicing professional is a systematic review. Methodically conducted reviews of the current literature can be used to answer clearly formulated clinical questions. The authors of systematic reviews classify the identified research by level of evidence. Data is collected across studies and a meta-analysis can be used to summarize the results of multiple studies (Dawes et al, 2005). On 12/4/09 the Cochrane Data Base of Systematic Reviews was searched using the key words, “assistive technology”, infants and toddlers” and “young

children”. No systematic reviews were identified pertaining to the use of AT with this population.

Although no systematic reviews were found in the Cochrane database systematic reviews on the application of AT with infants and toddlers, literature reviews have been located through other means. Campbell, Milbourne, Dugan and Wilcox, (2006) reviewed the evidence on practices for teaching young children to use AT devices. The authors searched several data bases for studies published between 1980-2004. The results of their search found only 27 empirical articles and 77 other articles pertinent to the search over the entire 25 year period. The authors used the AACPDm classification system to grade the studies. Of all the studies only one was graded as a level 1. 44% were level 2, 35% level 4, and 17% were level 5. A majority of the published studies used single subject designs. The authors concluded that there was evidence to support successful teaching practices for the use of switch controls and powered mobility, but evidence supporting teaching strategies for AAC and computer use was insufficient.

Generalized questions such as “Is AT an effective intervention for infants and toddlers with special needs?” may be important for program planning, systems change and guiding research agendas, but making evidence based recommendations in practice includes asking and answering specific questions about the care being provided to individuals (Dawes et al, 2005).

Infants and Toddlers with special needs represent a heterogeneous population, leading to the generation of a broad variety of questions about the selection, implementation and prognosis using AT as an intervention strategy. The broad category of AT can be described terms of function of the device (Cook & Hussey, 2003, Campbell et al, 2006). In this paper clinical questions about the use of AT to facilitate positioning, mobility, communication,

environmental control, and switch device interfaces are briefly examined for examples of research used in the evidence based decision making process.

Positioning

Question: For an infant with limited postural control can “low tech” assistive technology be use to enable the child to develop self feeding skills?

Initial searches for literature related to positioning of infants, identified several different types of research. Research that was not relevant to the question or pertained to populations with significant differences were disregarded. The rehabilitation professional looking for answers in the clinical setting there is a level of “trade off “ between the time needed to intensely review all possible literature and the selection of only the most relevant information with the risk of missing pertinent reports (Dawes et al, 2005). In this brief example, two articles of initial interest were identified. The was a review of the literature on the effectiveness of adaptive seating on postural control in children with cerebral palsy. The review was conducted systematically, and included the population relevant to infants with limited postural control. Only 14 studies that met the inclusion criteria were identified and graded using the AACPDMM system. The authors concluded only limited research with lower-level evidence is available to support the use of adapted seating for children with cerebral palsy.

The second article was an individual study but seemed more relevant to the question being investigated. Washington et al (2002), found an increase in postural stability using a contoured foam seat insert for a high chair. However this level II study only involved 4 infants and no studies have been conducted since then to further investigate results. The results of these studies are analyzed and integrated with information specific to the individual and family, to make an evidence based decision. However in this situation the rehabilitation professional

does not have strong evidence to support AT selection and would have to rely on judgment about the level and type of evidence available.

Mobility

Question: What type of mobility device can improve the gait pattern of a 2 year old child with cerebral palsy (CP)?

The use of AT to increase participation of infants and toddlers with mobility limitations is an area of active research. Devices such as orthotics (Looper, 2009) , wheelchairs (Butler, Okamoto, McKay, 1983; Jones, McEwen, Hansen, 2003; Wiart, Darrah, Hollis, Cook & May, 2004) and various other forms of mobility devices including an adaptive riding toy (Dietz, Swinth, White, 2002) have been referenced in the literature. Levangie, Chimera, Johnston, Robinson and Wobesky (1990) studied the effect of posterior rolling walkers and standard rolling walkers on the gait of children 2-10 years of age diagnosed with CP. The gait parameters of the children (n=13) in the study were analyzed. The authors found the use of a 4 wheeled posterior rolling walker was associated with better gait parameters for the children in the study. This provides the rehabilitation professional, child and family information about the effects of different types of AT, and although this was a small study, this would be appropriate information to use in an evidenced based recommendation for AT. Levangie also lead a team of investigators in a similar study looking at the effects of different walkers on the gait parameters of typical children (Levangie, Brouwer, McKeen, Parker & Shelby, 1990). These two studies could form the beginning of a series of in-depth studies to investigate factors leading to the selection of appropriate types of AT.

Augmentative and Alternative Communication (AAC)

Question: Would the use of an AAC voice-output device increase the participation of a two-year-old child with developmental delay and no verbal communication?

AAC is an approach that uses voice output devices, communication boards, signs and gestures as a means of communication (Ronski & Sevcik, 2005). Very few empirical studies have been performed with infants and young children. Campbell et al, (2006) found only one study with empirical evidence to support strategies for using voice output devices for young children with Autism. Since then a review of the research was performed by Light and Drager (2007) who reported a paucity of empirical research on the use of AAC by children under the age of three years. In this case the rehabilitation professional would need to decide if the results of the study could be extrapolated to children without autism, before using it to make an evidence based decision.

Switch Interface Devices.

Question: Would the use of a switch interface device increase the opportunities for individual play of an 18 month old child with limited motor skills?

Switch interface devices have been used with children as young as 3-months-old in the form of the mobile paradigm (Thelen, 1994) and have been successful used with a variety of children with disabilities. (Sullivan & Lewis, 1993; Cook & Cavalier, 1999; Daniels, Sparling, Reilly & Humphrey, 1995). There have been empirical studies on strategies to teach infants and young children to use switches (Campbell, Milborne, Dugan & Wilcox, 2006).

Typical infants have been successful with switch interfaces pulling strings attached to their wrists (Millar & Watson, 1979), activating a mobile through a tethered leg (Angulo-Kinzler, 2001; Heathcock, Bhat, Lobo & Galloway 2004) and touching canisters to activate a

audio/visual response (Millar, Wier & Supramaniam, 1992). Infants and young children experiencing atypical development have also been successful learning to use a switch interface to control a robotic arm (Cook & Cavalier, 1999), switch activated toys and computer programs (Daniels, Sparling, Reilly & Humphrey, 1995). Studies that compare typically developing children with atypically developing children have shown a longer duration is needed during the acquisition phase when learning to use a switch interface device (Heathcock, Bhat, Lobo & Galloway, 2004, Sullivan & Lewis 1993). Infants with movement limitations have used switch interface devices to increase self-initiated play experiences improving participation and increasing mastery motivation (Hauser-Cram, 1996). In this situation the rehabilitation professional can use information from multiple studies to make evidence based recommendations for the child.

Environmental control

Question: Can access to environmental control increase the participation of a two and a half year old child with multiple disabilities?

Environmental control is recommended as an area of intervention for infants and toddlers (Sooner Start, 2009). However in a data base search on December 5, 2009 no articles pertaining to the use of environmental control devices by infants and toddlers were located. Extrapolation of research for different populations (older children and adults) could be reviewed for information, however the rehabilitation professional has extremely limited ability to make an evidence based AT recommendation.

Summary of available research

The above examples provide just a snap shot of the types of research available to illustrate the range of levels of evidence that may be encountered by rehabilitation professionals.

It is beyond the scope of this paper to formally analyze all the research pertaining to the use of AT for infants and toddlers, and rehabilitation professionals should be aware that not all research studies are published and accessible through journals. Studies showing non-significant effects may be subject to publication bias and are less likely to be published in peer reviewed journals (Dawes et al, 2005). There are some examples of research showing the negative effects of AT use . An example of the negative effects of supra-malleolar orthotics (SMO) on gait for infants with Down syndrome is discussed in a dissertation abstract by Looper, (2009) and recommendation are made that SMO use is delayed until after the child has developed an established gait pattern and adaptive motor skills. There have been some studies on the effects of infant walkers on motor development. Changes in quality of movement and delayed acquisition of motor milestones have been reported (Siegel & Burton, (1999) and Engelbert, van Empelen, Scheurer, 1999). However the long term effects of the use of infant equipment on participation and disability has not yet been determined (Bartlett and Fanning, 2003).

Conspicuously absent from initial observations of the available research are serial studies that progressively build a strong body of evidence. Formal plans of rehabilitation research could involve a research series that uses multiple studies or multiple teams of researchers to independently verify results. The IOM (2007) recognizes the need for an integrated research agenda, and encourages collaboration across the many federally funded agencies with the objective of improving the available AT for people with disabilities. The current National priorities for rehabilitation research are summarized by the Disability and Rehabilitation Research Coalition's (DRRC) comprehensive recommendations to the McCain campaign (DRRC, 2008) these recommendations include the creation of a government-wide strategic plan for disability and rehabilitation research. The Interagency Committee on disability research

(ICDR) report on physical rehabilitation research also recommends a government-wide coordination of rehabilitation research (ICDR, 2007). The development of an integrated research agenda prioritizing the research needs in the area of AT would be an essential component of any interagency collaboration to increase the amount and quality of AT research including research across the lifespan.

Skills of the professional

In addition to the acquisition of pertinent research, evidence based recommendations require the professional to utilize and apply information to the individual circumstances of the child. The IOM (2007) recognizes the lack of awareness by both professionals and the public of available technologies. The IOM's recommendation 7.3, specifically addresses the need for public campaigns to increase awareness of AT.

Infant and toddler service providers identified a need for further training in AT (Long, Woolverton, Perry & Thomas, 2007). Only 18% of providers of early intervention services surveyed in 2006 viewed themselves as being well trained in AT. (Wilcox, Guimand, Campbell, & Moore, 2006). The IOM recognizes limitations in pre-service training curriculum for AT but acknowledges the need for health-care professionals to have a basic knowledge of appropriate technologies (IOM, 2007).

Barriers to Evidence Based Practice.

Progress in evidence based practice depends on the creation of good quality research, appropriate training of professionals and the recognition of limitations of the evidence based decision making process. These limitations include possible publication bias, inappropriate extrapolation of results, no or limited available evidence, poor professional judgment, a lack of a coordinated research agenda and limited research capacity.

Conclusion

The use of AT to alleviate disability and decrease environmental barriers is recommended for individuals with disabilities, including infants and toddlers. It is imperative that rehabilitation professionals who work with this population have the tools and skills necessary to make evidence based recommendations. Yet there is still a lack of adequate research and questions remain about the training and skills rehabilitation professionals have to make these recommendations.

In some circumstances, there is adequate information and skilled professionals who can and do make evidence based recommendations for the use of AT with infants and toddlers, however further coordinated research and training is required and recommended.

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DATE and TIME:	September 8, 2010	12:00 - 2:00 EDT
CALL IN NUMBER	1-888-808-6959	Code 6254120367
FACILITATOR:	Janice Miller; Room 125N	
NOTES TAKEN BY:	Haylie Smith	
LES Representation on the Call:	Bay	Annalise Campisi
("X" = LES participated on the call)	Big Bend	Cheryl Fitzgerald
	Central	
	Gold Coast	Kim Werner
	Gulf Central	Michelle Willey, Traci Volz
	North Beaches	Mindy McKee
	North Central	
	North Dade	Gwen Phillips
	Northeastern	Ann Milton, Kimberly Allmond, Elizabeth Tharpe, Lisa Lane
	Southernmost Coast	Christina Azor, Aldo Cossio
	Southwest	
	Space Coast	Vonda Gordon
	Treasure Coast	Kim McMahon, Kelly Bastien
	West Central	Eva Bryce, Toni Stansell, Pat Califano
	Western Panhandle	Penny Geiger, Lane Guess
	ESSO	Lynn Marie Price, Liza Smith, Haylie Smith, Patricia Herring, Kelly Purvis, Carol Burch, David Johnson, Anne Glass
	FSU	Terry Hoover
	AHCA	Gail Underwood
	OSEP	Hillary Tabor
	Children's Forum	Lou Ann Long

TOPIC	PRESENTER	RELATED DOCUMENTS/REFERENCES	OUTCOME
Update and Discussion with a Representative from the Office of Special Education Programs (OSEP)	Hillary Tabor	<i>Hillary will update us on the latest information from OSEP and she will also respond to the questions that were submitted.</i>	<p>Regulations for Part C are hopefully coming soon. They are currently at the Department of Education but there have been some delays. Reauthorization of IDEA is on the horizon. Hillary encouraged everyone to let ESSO know concerns, challenges, problems, etc... being seen in the field regarding the law and it's effect on implementing the program. Tentative date for reauthorization is sometime in 2012. Hillary opened the call to questions and the following items were discussed: (1) Eva Bryce - Foster care issue? Kelly Purvis responded that the issue is still being discussed with other state agencies, and expects resolution very soon. (2) Is there a powerpoint training for IFSP until the Service Coordinator apprenticeship modules are completed? There are directions on the IFSP Instructions that can be used. The modules will be unveiled at the statewide meeting; meanwhile the instructions have been revised to match policy but they do not repeat policy so you need to make sure the SC's are well versed in the policy and the directions. Liza highly encouraged individuals to attend the sessions at the statewide meeting along with the reflective practices sessions.</p> <p>(3) Maintaining a provider base is a problem and LESs are losing providers daily. (4) Natural environment is very difficult to implement due to the reimbursement rate for providers. (5) It was shared that PTs are now required to have a doctorate degree to graduate and be able to provide services anyone- Gold Coast stated that existing PTs will be grandfathered in if they will stay with the birth - 3 population. Many PTs are moving away from serving the pediatric field- to serving kids 8 years and older.</p> <p>(6) Penny Geiger stated that payer of last resort is difficult- easier if LES could have insurance and Medicaid and Part C come together and be more fluid. Would help to have a system that pays per child not fee for service- breaking a team apart for serving a child makes it very hard when billing. (7) Inactive children who are lost or cannot be located still have to be kept in the system. If everything possible is done to find them but still unsuccessful, why can't we close them? Hillary stated that this is an issue that will be taken back to OSEP and discussed to see if some relief can be found. (8) Foster Care families - getting appropriate signatures, meeting timelines, etc... are a challenge. Would like more clarification as to whom can sign and preserve the parental rights.</p>

			(9) With Tri-Care insurance- if a therapist does an evaluation and another provider provides the ongoing services (a change in authorization) right now Tri-Care will make the 2nd provider complete another evaluation-- they do not accept the authorization. LESs are having to cancel evaluations because of this. (10) Providers are waiting for payment and LESs are waiting on insurance denials which can take 3-4 months and in the meantime the provider quits. Hillary stated that it might help to make sure the providers know the philosophy of the program. The purpose is to focus on the developmental piece and not so much on how many services are provided and for how long. The purpose is not to replace the medical services that the child may need. (11) Hillary stated that many states are questioning where to house the Part C programs. Some are in Health and some in Education. (12) Lynn Marie stated that we are working on public relations information for families and providers to project a clear image about who we are and what we do. It will be a slow moving process. We need to be clearer about who we are and what we do. This will also be embedded in the service coordinator training modules.
Family Survey Update	Kelly Purvis		Kelly thanked everyone for their participation in the survey process. Indicators 4a,b,c, are not completed yet. Those results will be shared in the future. The results for the distribution and response rate are complete and will be shared in the weekly memo. Kelly reviewed and discussed the statewide numbers. The response rate increased 1% from last year's results. She encouraged LESs to look at the mechanisms in which the surveys were delivered to families and analyze which mechanisms worked best based on the yearly results. 90% of the surveys sent out statewide did reach families. Kelly will be bringing a team of "advisors" together to analyze the data at the statewide and local levels. Anyone who would like to be a part of the team, please email Kelly.
Individualized Family Support Plan (IFSP) Update	Carol Burch		ESSO is working on a few updates to ES policies and forms to become effective October 1, 2010. The DOH Webmaster has just inadvertently posted working draft IFSP Forms and Instructions (dated 8/10), so these web files should be ignored; once the files have been finalized (dated 9/10) and posted the field will be notified, along with specifics of the changes. Updates include the removal of race and ethnicity questions from the IFSP Form A, which is to be gathered instead through Intake or Data Collection forms that are being used by each LES.
How to Handle "Inactive Children" in the Data System	David Johnson		Kim Warner sent helpful instructions which explains their process on how they select the reports, enter the date range, generate the reports, etc... When an active case list is run, you need to change the closure code from "I" (Inactive) to "1" (lost to followup), the closure date to the 3rd birthday, and the closed before field to a "Y".
Statewide Meeting Update	Liza Smith		Reminder that the statewide meeting is September 29-October 1. Everyone planning to attend should have already made hotel reservations and completed registration for the meeting. In an effort to be green and cut back on the use of paper, we are going to post much of the information needed for the meeting on our website (agenda, breakout session descriptions, etc). Closer to the date, we will be posting the PowerPoint presentations for the breakout sessions for those who wish to have hard copies prior to the meeting. After the meeting, all materials will remain posted on the web.
Race and Ethnicity	David Johnson		David has created an additional supplemental document for use in collecting race/ethnicity data with families which was emailed to everyone earlier. David reported that you can stop requesting mother's race and just enter unknown in the system. Reminder, if you have your own demographic data collection forms please add the fields to collect the child's race and ethnicity information. The handout that was emailed is to provide information about what the race and ethnicity is and why we collect it. It contains the Hispanic list and recognized American and Alaskan Indian tribes. Reminder: The individual is to self identify their race if possible. If you must identify their race for them, a key indicator that could be used is their language. If it is not clear, even after using info provided by the individual and resources provided by ESSO, a decision must still be made by the person requesting the info for data collection.
			Please note that the way this information is presented to the family makes a big difference in the success of obtaining accurate info and also whether or not the family finds it offensive. (What race and ethnicity are people from Mexico and Puerto Rico? The answer is that the majority are Hispanic and White as they are descended from Europeans (Spain) if they cannot self identify.)
Next Call			There will not be a call in October. The next call will be on November 10 from 12:00 - 2:00 EDT (The Conference Call Telephone Number and Code is the Same)

Survey for XXI Payment

Purpose: In order to analyze the data regarding Title XXI payments and services, we need to know how you are collecting the data in your service area. As you recall, last May you voted on your preference for the future billing process. We need to know the following:

1) Do any of your providers directly bill CMS for Therapy or Early Intervention that are identified on IFSPs for children enrolled in Title XXI? Y__ N__

If yes, are these services reported to you and entered into the UF Early Steps Data System?

If yes, what payor code(s) are used in the intervention records?

2) For services provided directly by your agency to children enrolled in Title XXI, what payor code(s) are used in the intervention records?

3) Do your procedures as outlined in the responses to the questions above impact whether or not you bill the Per Member Per Month to CMS for any children?

FSDB Outreach Services / Parent Infant Program Training Registration

Specialized training for working with young children with sensory loss and their families in natural environments is available for professionals with a background in sensory loss, child development, special education, speech/ language pathology, audiology, physical and occupational therapy, social work, and other related fields. If you have any questions please contact the Parent Infant Program staff: 904-827-2232 or 904-827-2257, FAX: 904-827-2293 or email: carrk@fsdb.k12.fl.us or strasselg@fsdb.k12.fl.us

To register for this training, please check the training you want to take and complete the form below.

_____ **VIISA (0-3) March 25-26-27 and May 20-21-22, 2011**
For working with families/caregivers with children birth-3 with a vision loss, home-based

_____ **VIISA (3-5)**
For working with children 3-5 with a vision loss and their families, center-based

_____ **SKI-HI Jan. 21-22-23 and Feb. 25-26-27, 2011**
For working with families/caregivers with children birth-5 with a hearing loss

_____ **INSITE Oct. 15-16-17 and Nov. 12-13-14, 2010**
For working with families/caregivers with children birth-5 with a sensory loss and additional disabilities

Name: _____
Address: _____
City State ZIP
Telephone: _____
Home Work FAX

E-mail Address: _____
BACKGROUND INFORMATION
Degree/Major: _____
Certification: _____
Title/Job: _____
Description of Present Position:

EXPERIENCE:
What experiences do you have working with young children or families of young children with sensory loss and/or other challenges?

Please check below to indicate your understanding and agreement with the conditions specified.
_____ "I realize that I must complete all sessions of the Parent Advisor Training to be certified. The certification is valid for 5 years at which time it can be renewed. I also acknowledge that I am aware that there will be independent homework assignment(s) between the training sessions.

_____ "My program and I are willing to participate in the ongoing Technical Assistance offered by the Florida School for the Deaf and the Blind, Parent Infant Program, as part of my Parent Advisor Training. This Technical Assistance is offered at no cost to me or my program."

Please return to:
Parent Infant Program _____
Florida School for the Deaf and Blind signed date
207 N. San Marco Ave., St. Augustine, FL 32084
FAX # 904-827-2234