

Homebound instruction for students with chronic illness: reducing risk outside of the box

Students with chronic illness are at risk for a host of academic and social problems. The risk is exacerbated when students are unable to attend school short term or long term due to medical problems. Educators may be able to reduce academic and social risk for students with chronic illness through effective homebound instruction. However, there remain many barriers to effective homebound instruction. Effective interdisciplinary and community coordination, development of policies, teacher support, inclu-

sion of families, and use of technology can be combined to overcome these barriers and create effective homebound programs and policies. The result is reduced risk for the large and vulnerable population of students with chronic illness.

KEY WORDS

chronic illness; homebound instruction; educational policy; medical issues; technology

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Students with chronic illness are at risk for a host of academic and social problems (Brown & Bolen, 2003; Erickson, Patterson, Wall & Neumark-Sztainer, 2005). School drop out, declining academic performance, mental health problems, loss of friends, alienation from peers and educators, and other negative outcomes are more common for students with chronic illness than for their healthy peers (Armstrong, Blumberg & Toledano, 1999; Bowman, 2001; Thies, 1999). The risk is exacerbated when students are unable to attend school due to medical issues (Cook, Schaller & Krischer, 1985; Ela, 1995). Educators may be able to reduce risk for students with chronic illness through inclusive educational practices. However, in many cases such education will take place out of the box of the traditional classroom environment.

Formal instruction in the home occurs in a variety of situations. Early childhood education systems frequently provide speech and language therapies, behavior management consultation, physical and occupational therapies, applied behavior analysis, and parent education in a home setting (Patterson & Tullis, 2007). In the US, home-based education is commonly a part of the Individualized Family Service Plans for children aged three to five years that is mandated by Federal law (*Individuals with Disabilities Education Improvement Act* – IDEIA, 2004; Sirvis, 1988). Such home-based education is especially common for children diagnosed with autism spectrum disorders (Patterson & Tullis, 2007). In this fashion, early educational and therapeutic interventions can be started at an early age, take place in a convenient setting, and involve parents in the process.

Home-based instruction may also include instruction in the home for students receiving special education services (Patterson & Tullis, 2007). In this context, home-based instruction is the most restrictive environment in which special education services can be provided. This form of education is often used for students with severe behavioral problems that are considered to be a threat to students or staff in the school environment. Sometimes students with severe intellectual disabilities, uncontrolled hyperactive behaviors, sensory impairments, and severe motor impairments result in home-based education (e.g., NC Exceptional Children's Division, 2000). Often this form of instruction takes place when the schools have limited resources to effectively educate and manage these students with special needs in the school environment (Tate, 2000).

In contrast to early childhood education and home-based instruction for students with special needs, homebound instruction is a system of educating students who are unable to attend school due to illness (mental or physical) or injury (Shaw, Glaser & Ouimet, 2011). Homebound instruction involves a certified teacher entering the student's home to provide individualized instruction (Macciomei & Ru-

ben, 1989). Although the responsibilities of school personnel to provide specialized educational services, hospital-based education, reintegration/transition assistance, or accommodations for students with chronic illness are widely described in the medical and educational literature; homebound instruction is rarely addressed in the literature or addressed in educational policies (Shaw, Glaser & Ouimet, 2011). Homebound instruction is a program that was developed from a patchwork of educational policies in the US (e.g., *South Carolina State Board of Education #1819*; NC Exceptional Children's Division, 2000), statutory law (IDEIA, 2004; *Section 504 of the Rehabilitation Act of 1973, 1973*), case law (*Cedar Rapids Community School District v. Garrett F, 1999*), and innovative local programs (Case & Matthews, 1983) to provide educational instruction for these students in the safety of their homes. Related programs have been developed throughout Canada and Europe.

Eligibility, staffing, procedures and programming vary considerably across school systems. Many school systems have no established or documented policies other than a general statement that homebound educational services will be provided in some situations (Ela, 1995). Therefore, decisions of homebound eligibility are often made on a case-by-case basis without formal criteria. In addition, the few school systems with detailed policies emphasize different aspects of eligibility for homebound instruction (Nader, 1993). For example, uncomplicated pregnancy is a common reason for homebound instruction eligibility in some schools (Thies, 1999); others have specialized programs or expect students who are pregnant to attend regular classes. The lack of consistent eligibility criteria makes broad statements about homebound instruction eligibility difficult (Shaw, Glaser & Ouimet, 2011).

Most students who are eligible for homebound instruction have one of five problems: acute medical condition such as injury, contagious illness, or infection; chronic medical conditions such as sickle cell disease, asthma, or compromised immune system; rehabilitative care for students with mobility issues, recent paralysis or sensory loss; pregnancy; and mental health issues with psychiatric diagnoses (American Academy of Pediatrics, Committee on Children with Disabilities, 2000; Newacheck *et al.*, 1998). The intent of homebound instruction is to continue the education of students with medical issues that preclude attendance in the school building.

MAJOR FEATURES OF HOMEBOUND INSTRUCTION AND BARRIERS

The American Academy of Pediatrics (AAP), Committee on Children with School Health (2000) recommends four major features for homebound instruc-

tion: a) All work in a homebound program mirror the amount of work, content, and progress of students in the classroom; b) The child's condition be carefully monitored to determine whether the child presents risk to others due to contagion or aggressive behaviors before returning to school; c) Parents are required to be available for supervision and support during all homebound activities involving a teacher being physically present in the home; and d) The hours of homebound instruction and work required consider the health status of the student. These guidelines were put forth by physicians, whether the schools consult or follow these medical recommendations is unclear. There are significant barriers to providing effective homebound instruction, as described. Simply attempting to reduce the risk for students involved remains a significant challenge in the educational system.

MIRRORING AMOUNT OF WORK, CONTENT, AND PROGRESS

Most students receiving homebound instruction receive about 45 minutes of instruction per day (Shaw, Paéz, Powers & Eggert, 2001). A major pedagogic barrier is that one hour of instruction in the home cannot possibly mirror the educational experience of five to seven hours of instruction received in the traditional classroom. The average student who attends grades Kindergarten through high school spends at least five hours per day receiving instruction from teachers (Kaufman & Herman, 1991). Of those five hours of instruction, at least three and one-half hours are dedicated to the core subjects of reading, mathematics, science, and social science (Kaufman & Herman, 1991). Over the course of a 180-day school year, each student attending school receives a minimum of 630 hours of instruction in the four core subjects. Moreover, there is frequently homework assigned for practice activities, research, and projects for students attending school in addition to the 630 hours of classroom instruction. Under ideal conditions, the average student receiving homebound instruction receives an average of one hour per day with the homebound teacher, 180 hours per year of instruction in the four core academic subjects, equivalent to 29% of the instructional time as students attending school. This difference likely increases the achievement gap between students with illness who are receiving homebound instruction and their school-attending peers.

The typical student receiving homebound instruction program will need to complete approximately two and one-half hours of independent school work, in addition to the less than hour of teacher-led instruction, each day to match the amount of instructional time dedicated to the core academic areas. Students receiving homebound instruction not only

have two and one-half hours of independent work, there are also routinely assigned homework and long term projects that may total as much as three additional hours of independent work per day. The possible total of five and one-half to six hours per day of independent academic work is a high expectation for students with medical conditions or psychiatric issues. Moreover, few students, especially younger students, will learn as much in independent work as they would if engaged in interactive, mediated educational experiences with teachers and peers (Reamy, 1988).

ELIGIBILITY AND MONITORING THE CHILD'S CONDITION

The AAP Committees on School Health (1993, 2000) and the AAP Committee on Children with Disabilities (2000) describe several barriers from the physicians' point of view related to homebound instruction (AAP, 2000). These barriers are: lack of clarity concerning which medical conditions should result in a child's exclusion from school, uncertainty about the responsibility and administration of complex nursing and medical therapies that are educationally related, conflicting opinions about the propriety and educational relevance of some therapies, concerns about the cost to schools of homebound and related services, and appropriate services to students with severe medical issues who are not considered to be eligible for an Individualized Educational Plan. Physicians are often uncomfortable with their eligibility role and responsibilities given their relative unfamiliarity with education law and varying criteria for special education and homebound eligibility (Shaw & Woo, 2008).

Given the primary role that physicians play in determining eligibility and communicating medical progress to educators, the lack of clarity and poor communication can be major barriers (Shaw & Woo, 2008). Schools and physicians are best served when there is advanced planning as to which medical and mental health conditions are appropriate for homebound instruction (e.g., meningitis), which may not be appropriate (e.g., school refusal and anxiety disorder), and which require professional judgment (e.g., sickle cell disease). When roles and responsibilities are clear, then collaboration can be most effective (Shaw & McCabe, 2008). School-medical liaison teams can act to develop clear local policies that best serve the needs of the community (Shaw, Glaser & Ouimet, 2011). Often members of school-medical liaison teams include community medical professionals, community health clinic personnel, school nurses, and school administrators.

Among the most important role-clarifying statements in a homebound policy is the development

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of responsibilities for determining eligibility (Shaw, Glaser & Ouimet, 2011). For example, to be eligible for homebound educational services a medical referral form with a specific diagnosis must be submitted to the local school district completed and signed by a licensed physician. This medical referral form verifies that the illness, injury, or mental health problem confines the student to the home for a significant length of time. Included in this form shall be a statement by the physician that the student will be absent a minimum of 15 school days, an estimate of the total days missed, and development of a transition plan for return to the classroom. In the case of mental health issues, a physician or licensed mental health professional (the legal mandate for which professionals are charged with making mental health diagnoses varies across states and provinces) verifies the severity of the mental health issue and includes a diagnostic code (e.g., ICD-10 or DSM-IV-TR). Also included in the medical referral form is an estimate of best knowledge as to the degree that the illness may be communicable (when appropriate) or may result in a danger to other students or staff (e.g., violent behavior). Homebound instruction is time limited based on the best estimate from the physician. When the time limit is reached, a new medical referral form must be completed or the child can be transitioned to the traditional classroom setting.

PARENT INVOLVEMENT AND THE HOME SETTING

Due to there being two and one-half to six hours of independent work per day assigned to the students in homebound instruction, the parents of these students are forced to become *de facto* home-school teachers. Responsibility is placed on the parents to educate their child; or at minimum supervise the student's independent work. Not all parents are willing or able to assist in the formal education of their children. Moreover, parents of students receiving homebound instruction often have many roles: nurse, emotional supporter, financial supporter, advocate, and dietician in addition to the already busy job of parent. Adding fulltime teacher to the parent's role is an additional stressor (Carrera, 2003; Johnson, Lubker & Fowler, 1988).

The families' responsibilities are to be communicated before instruction can take place (AAP Committee on School Health, 2000). Homebound instruction requires that a parent, guardian or caregiver be present and available during all homebound instruction sessions (AAP Committee on School Health). The family must establish a quiet, clean, comfortable, and well-lighted location for child and teacher to work. The family is responsible for notifying the teacher as soon as possible if the homebound session is to be

anceled or postponed for any reason (e.g., medical or therapy appointments, pain, fatigue). The family is also responsible for communicating changes in the child's medical status that are relevant to instruction or method of service delivery.

Physical environment and conditions under which homebound instruction occur create another barrier to effective homebound instruction. Parents and/or caregivers must be present in the home when the teacher provides instruction. This may cause problems because homebound instruction may take place any time of day and is often after the normal school day ends. Parents who work or have other responsibilities may find the homebound instruction schedule difficult to maintain (Carrera, 2003). Moreover, scheduling instructional time around therapies, doctors' visits, and nursing is often a challenge. A quiet place in the home devoted to instructional time is not easy to develop in some homes. Some homes and neighborhoods may be dangerous and otherwise not conducive to education. Teachers have the right to refuse homebound instruction if they believe that the teaching environment is not safe (AAP Committee on School Health, 2000).

INSTRUCTIONAL FLEXIBILITY

The potential advantage of homebound instruction is that continuous assessment and individualization of instruction can take place. Students with medical or psychiatric problems change quickly in terms of the health status, response to medications, energy level, and academic motivation (Ainse, 1981). The child may experience significant pain, nausea, or fatigue that is inconsistent with academic effort (Shaw & McCabe, 2008). Teachers require knowledge of such changes through continuous communication with parents. Flexibility is required in terms of moderating workload or type of instruction. However, the threshold for canceling a homebound instruction session is much higher than the threshold for not attending school. Many students will try to find reasons to avoid academic work in homebound instruction just as in the classroom. One of the goals of homebound instruction is to normalize life for students in addition to helping students to keep pace with their peers (Nader, 1993).

DEVELOPING EFFECTIVE HOMEBOUND PROGRAMS AND POLICIES

Nearly every school district will be faced with the need to conduct homebound instruction. The numbers of children with chronic illness is growing due to improved survival rates of some life-threatening

illnesses and greatly reduced amount of in-patient care in favor of increased outpatient care (Shaw & McCabe, 2008). Simply because homebound instruction is a highly individualized method of educational service delivery does not mean that policy development and planning should be ignored. For example, because most schools do not have well considered policies and have not considered how to maximize the effectiveness of homebound instruction few school districts actually use technology. Yet, effective use of technology can be important in overcoming several of the above described barriers to effective homebound instruction. In addition to addressing the four major features highlighted by the AAP, homebound programs and policies require multiple considerations.

ADMINISTRATIVE SUPPORT FOR TEACHERS

The homebound teacher is required to be an expert in all subject areas. Homebound students typically receive homebound instruction from one teacher; yet require information in several different subject areas. At the elementary level, this is usually not a problem because most teachers have knowledge of the variety of topics presented during these grades. At the secondary level, there is greater specialization in subject areas. The course material may be too detailed for one teacher to effectively teach the four different core subject areas, yet the homebound teacher is expected to do so. Given the US mandate of *No Child Left Behind* (2002) that all teachers be “well qualified” in every academic area in which they are teaching, this issue can be an administrative burden.

The homebound teacher is responsible for acting as liaison between the school-based teacher and the family (Shaw & Woo, 2008). The homebound teacher is responsible for bringing all assignments and communications from the classroom teacher and the home (Venn, 1989). Also, the homebound teacher should also be aware of communication that takes place between school-based teachers and families (Clay *et al.*, 2004). For example, the homebound teacher should be copied for all e-mail messages between school-based teachers and families (Frieman & Settel, 1994). The homebound teacher consults frequently with the school-based instructor concerning the lessons to be taught for the day. In this fashion, some basic level of teacher expertise can be delivered to the student.

Effective homebound teachers develop relationships with children and families. This relationship between teachers and children and families is the most effective approach to overcoming many barriers to effective homebound instruction (Johnson *et al.*, 1988). Some teachers provide instruction to the same families for two or more consecutive years in cases of students with severe chronic conditions. Often

homebound teachers and families become emotionally close. Although the relationship between teacher and family is important there is a downside. Some students with severe medical conditions will succumb to their illness or injury (Ainse, 1981). Some students with psychiatric issues may require institutional care or become suicidal (Venn, 1989). Teachers do not often have the training or experience to cope with the issues of their students dying or being removed from the home (Bowman, 2001; Carrera, 2003). These difficult situations are exacerbated by the closeness of student-family-teacher relationship that is typical of effective homebound instruction. In all homebound instruction situations plans for the involvement of teacher support groups, mental health counselors, and administrative support is essential to assist homebound teachers in these most emotional and difficult of teaching activities.

COSTS AND RESOURCES

Homebound instruction is typically expensive and inefficient. Having several homebound students receiving individual instruction and tutoring may strain resources in some communities (Case & Matthews, 1983). Extra copies of textbooks, teacher time, technology, and mileage reimbursement for the teacher add up to significant expenses. However, the most expensive component of homebound instruction is, by far, personnel costs. Not only the time of the homebound teacher; but the time for the school-based teacher to prepare and grade assignments, administrative time to allocate resources and coordinate services, professional time to hold educational programming meetings, and clerical time to track changes in the model of service delivery add up to significant costs above and beyond regular and special education services. The high costs and less than efficient service delivery approaches can be addressed with changes to the methods of instruction.

TECHNOLOGY

The adoption of technology, both hardware and software, can dramatically reduce the heavy costs associated with homebound instruction. The application of technology to distance learning generated by community colleges, some universities, and rural areas for distance learning has important applications for homebound instruction (Moore & Kearsley, 2005). However, because most school districts do not have well-considered policies or have considered how to maximize the effectiveness of homebound instruction few school districts use technology for homebound instruction (Morgan, 1990). The proper application of technology can drastically improve areas of diffi-

culty associated with homebound instruction. These areas include planning, instruction, communication, scheduling, and delivery of important material.

Acquiring hardware and software is not usually a major difficulty. Many schools engage in business partnerships so that computers, fax machines, and other equipment are donated to schools. Grants are available through the US Department of Education, state and provincial governments, local and regional foundations, and other government agencies to promote the use of effective distance learning. Of course, many families of children receiving homebound instruction already have home computers and/or fax machines. Laptop computers with a wireless or broadband internet connection can even be purchased for significantly less than \$500. Schools could save significant resources by providing such computers with internet connections to families. Some major communication companies are developing and piloting distance-learning programs (e.g., Verizon). Access to hardware and software is rarely a problem, but some creativity is required.

Technology does not always require complex interactive teaching techniques. Technology should be used to compliment homebound instruction. Acquiring the technology is not the issue: accessing it during proper times while considering the demands of the child, parents, or physicians is. One-way communication is a set of simple technologies that provides information, but likely plays a limited role in increasing teacher-mediated academic engagement. Examples of one-way communication are videocassette tapes or digital video disks of classroom lessons, CD-ROM versions of books, accessing classroom and school websites, and accessing other instructional websites on the Internet.

Two-way communication allows the student to have an interactive and mediated educational experience using technology. A low-tech method of two-way communication is a speakerphone connection. In this fashion the students are able to hear the lecture, all classmates' comments, and are able to contribute to the class. This method is rarely feasible, as issues of scheduling, permitting time, and parental involvement remain.

Many teachers have their own classroom website on which schedules, due dates, notes, and assignments can be posted. Webcam information can be recorded as audio or video podcasts and posted on the teacher's website, then heard or viewed when convenient. In addition, supervised class chat rooms or message boards can valuable interactive resources for the homebound student. For example, it takes little effort to set up a chat room that is only open to members of Mr. Smith's 10th grade History class. In this fashion, students and the teacher could engage in discussions, peer support, homework help, and shared assignments.

Different technological tools and programs, when implemented with proper scheduling, can simplify homebound instruction, reducing costs and the physical resources required for effective teaching. They also allow students to experience a more integrative and active learning experience, an issue not only experienced for students at home, but also for those in class. Google Hangout is an easy and effective way for teachers to get in touch with their students one-on-one, face-to-face. Teachers may also use Google Hangout to deliver a specialized teaching session to a student, rather than running through the numerous issues and costs associated with visiting the student at home. This can be complimented with cloud storage technologies, such as Dropbox and Google Drive, allowing for simple delivery of lesson plans, information, and exercises. Furthermore, simultaneous editing of a document by both teacher and student can be achieved on Google Docs (now on Google Drive). This provides instant oral feedback which is complimented with instant on-screen changes to a document. Finally, Edmodo provides an instructor a simple interface to deliver polls, materials, and quizzes online, while at the same time allowing instant feedback to students with a messaging service.

Instant messaging and e-mail are basic methods of interactive communication that can provide immediate feedback from teachers and peers. A promising technological innovation is the implementation of mobile learning or m-learning (Wang, Shen, Novak & Pan, 2009). As there are more than 2.7 billion mobile users in the world today (Ahonen & Moore, 2007), the use of m-learning can not only benefit students attending school, but those who are homebound due to chronic illness. Traditionally, mobile learning involved passing information to students via short message service (SMS). This SMS reminder prodded students into action and helped to keep them on track with their work (Thornton & Houser, 2005).

Research and implementation of mobile learning (m-learning) has now concerned itself with issues normally of concern in the classroom: integrated and active learning. Researchers in the E-Learning Lab and Network Education College of Shanghai Ji-aotong University have developed an m-learning program with positive feedback (Wang, Shen, Novak & Pan, 2009). This m-learning system involves students connecting via smartphone to a network, downloading and installing a client where they can view their curriculum, and connect to any live classes currently in-progress. They will connect to a live feed of the instructor and the PowerPoint being used. Once a student connects, the instructor received periodic screenshots on their own interactive screen of the student's mobile device to monitor the progress of the student. Students may also send SMS messages to the instructor, which appear on the instructor's display. The instructor may then immediately answer the

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question orally, or send a short message reply to the student. Furthermore, students on their devices may also participate in polls initiated by the instructor based on the material, or for feedback on presentation pace and clarity (Wang, Shen, Novak & Pan, 2009).

M-learning systems attempt to create a natural context for learning when a student is unable to attend class. M-learning faces limitations that may hinder its use for homebound instruction. These limitations include the current limited storage capabilities of mobile devices (Wagner & Wilson, 2005), and size restrictions of mobile device screens and input mechanisms (Hayes, Joyce & Pathak, 2004). It would be difficult to implement m-learning in a high school setting for homebound students. Technological constraints exist in the classroom and time constraints exist for the homebound student, making it difficult to attend every lecture. M-learning can provide a homebound student and instructor another venue to hold interactive sessions. Many students own smart phone devices, making m-learning a viable, time-efficient, and cost-efficient route to homebound instruction.

There is more to effective homebound instruction than ferrying school work to the home of a chronically ill child. The technologies outlined exist and are currently vastly used for purposes other than homebound instruction, but must be considered as viable alternative to traditional homebound instruction methods. The recommendations from AAP are an excellent place to begin to consider other options. However, there are several other important aspects of an effective program.

CRITICAL POINTS IN A HOMEBOUND INSTRUCTION PROGRAM AND POLICY

Few schools have specific homebound policies or programs. Most schools decide on the needs for homebound instruction on a case-by-case basis (Ela, 1995). This reactive approach usually leads to capricious eligibility decision making and poorly planned instructional activities. Below is a sample of the critical points to be covered in order to be consistent with AAP guidelines, statutory and case law mandates, and principles of effective distance education.

Eligibility and medical responsibilities. Eligibility guidelines are to be developed in coordination with medical, community, and educational stakeholders. Values of the community, consideration of available resources, and consistency with local, state, and national legal requirements are integrated to make policy (Macciomei & Ruben, 1989). Including community medical resources is especially important in deciding which medical conditions are to be considered for homebound instruction. For example, eligibility and medical responsibilities must be integrated with previously developed IEPs.

School administration responsibilities. The homebound instructor is to be given appropriate administrative support in terms of materials, technology, logistics, copying, postage, textbooks, and computer equipment required to provide effective homebound instruction. A homebound teacher support system is to be made available to address professional, expert, administrative, and emotional needs of all homebound instructors.

Homebound teacher responsibilities. The homebound instructor must be in daily communication with the school-based teacher. Teachers require knowledge of the changes in the child's medical condition and readiness to receive education through continuous communication with parents. Teachers do not have to provide homebound instruction if they believe that they are in physical danger. The family and homebound instructor are mutually responsible for attaining needed books and other materials necessary to complete schoolwork. Technology to improve the quality of homebound instruction is to be negotiated between the parent and school. Homebound teachers need to have familiarity with and can educate families on how to use the technology.

Family responsibilities. Parents and caregivers have responsibilities that include being present during each homebound instructional period; providing a safe environment; providing a quiet, safe, well-lighted, and appropriate place for the child and instructor to work. Parents are required to notify the homebound instructor in advance if the student is unable to receive instruction at the appointed time.

By weaving these details with local regulations, laws, and other issues a comprehensive homebound policy and instructional methods can be developed.

CONCLUSIONS

Homebound instruction is intended to mirror the academic curricula in the school setting. There is also the intent of working with medical personnel to develop a physician-educator team for the benefit of students. However, there are enough questions and concerns from physicians and from a pedagogical perspective to question whether the intent of homebound instruction is being realized. Barriers can be addressed with effective and cost efficient use of technology and developing and communicating a coherent policy on homebound instruction. Above all planning, advanced communication with educational and medical professionals in the community, and the development of a comprehensive homebound policy are required to overcome the significant challenges inherent in homebound instruction.

Homebound instruction is not the ideal method for a student to receive schooling. Traditionally, homebound instruction is a method of education-

al service delivery that is only preferable to no instruction at all. However, with thought and planning homebound instruction can not only an effective stop-gap method of uninterrupted instruction, it can add to the normalcy of the lives of children whose lives are anything but normal.

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