

## Evaluating an Effort to Improve Parents' Ability to Obtain Educational Services for their Chronically Ill Children: Lessons from Project PENCIL

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A common public health question is how to effectively provide educational services to school-aged children with chronic illnesses. These children, whom we identify in this brief as “chronically ill learners” or “CIL,” suffer from a range of mild to severe chronic illnesses, such as asthma, HIV/AIDS, diabetes, cancer, sickle cell anemia, cystic fibrosis, among others (Kaffenberger, 2006; Taras & Potts-Datema, 2005; Moonie et al., 2006). There are an estimated 4.4 million CIL in the United States who miss school annually because of chronic illnesses (Kaffenberger, 2006; Shaw & McCabe, 2008). The average annual number of days that a child is absent from school varies by chronic illness, ranging from roughly eight to 12 days for a child with asthma to as many as 80 days for a child with cancer, but, on average, a child with a chronic illness is absent 16 days per year, compared with three days for a typically healthy child (Moonie et al., 2006; Vance & Eiser, 2001; McDougall et al., 2006).

School absences cause an array of problems not only for CIL, but also for their parents. These children can fall behind in their academic coursework and fail to properly socialize and form friendships with their classmates, producing stressors that compound their chronic illnesses. Their parents may miss work and bear other costs to cover school absences, producing their own stressors. What makes this problem particularly vexing for children and their parents is not only the number of days absent, but also their typically intermittent nature. Indeed, instead of missing class time continuously, CIL often bounce in

and out of school, compounding academic and social issues and making solutions for parents to help them particularly difficult (See Kearney 2008 for a discussion of the effects of intermittent absences).

The academic, social, and stress-related consequences of chronic illness and intermittent absences on CIL and their parents can be mitigated through the effective provision of school-based services, which typically include in-class supports and accommodations, such as curriculum modifications; plans for administering medicine during class time; make-up assignments for missed work; and in-home instruction. These services can smooth the transition of CIL in and out of school, but despite their importance, many CIL are ineligible for them until a team of health and school professionals document that the CIL's illness adversely impacts his or her academic performance, a process that can take months and often involves persistent advocacy by parents (Eaton, 2012; Aron & Loprest, 2012; Thies, 1999). However, many parents have limited knowledge about the availability of educational services to help their CIL, how to obtain them, and, once obtained, how to manage them. Indeed, even once services are in place, managing them may continue to take parents' time, such as missing work to administer medications at school (Wilson et al., 2005). It is unsurprising that understanding, securing, and managing educational services for CIL can be stressful for parents.

## Project PENCIL's Parent Component

That parents are instrumental in obtaining and managing educational services for their CIL, but can lack the knowledge to do so, creates a need for an effective public health intervention. To that end, the National Institutes of Health funded the development of Project PENCIL (Protecting the Educational Needs of Chronically Ill Learners), a training program that aims to effectively address the academic and social needs of CIL through the supply of educational services. Project PENCIL contains training components for both parents of CIL and their teachers, and an evaluation of the prototype of Project PENCIL's teacher component can be found elsewhere (Palmer et al., 2014). This brief focuses solely on the evaluation of the prototype of the parent component.

More specifically, the parent component of Project PENCIL aims to significantly increase parents' knowledge about the educational services available for their CIL. In tandem, it aims to significantly improve parents' attitudes and self-efficacy to understand, advocate for and secure, and manage educational services for their CIL, which, when coupled with increased knowledge, completes the model that knowledge, attitudinal, and self-efficacy changes predict positive behavioral change (Bandura, 1977). In this case, the predicted change is the more effective acquisition and management of educational services for CIL.

In its prototypical form, the parent component is a 60 -page print guide with six sections, including (1) an introduction to the guide, (2) a description of six steps for parents to secure educational services, (3) a description of educational accommodations to mitigate the academic and social effects of various chronic illnesses, (4) contingency plans to work with a school if parents cannot secure educational services or schools fail to properly implement them, (5) additional resources for parents to obtain more information about topics in the guide, and (6) a contact list of national advocacy organizations for common chronic illnesses, plus appendices with information sheets. In its final form, the parent component will include a print guide and an interactive knowledge and skills-building website and video testimonials from parents of CIL.

## Methodology

The underlying hypothesis in the development of Project PENCIL's parent component is that, when equipped with improved knowledge, more positive attitudes, and stronger self-efficacy, parents will be able to develop and implement better tactical skills to more successfully acquire and manage

educational services for their CIL and, as a result, experience less stress from the compounding effects of chronic illness and intermittent school absences. To address this hypothesis, we used a two-group, pretest/post-test, quasi-experimental design with 50 parents of CIL in Kindergarten through 5<sup>th</sup> grade. We recruited parents nationally and from several socioeconomic backgrounds and randomly assigned them to an experimental group or a control group. They took separate online pretest and post-test surveys that assessed their knowledge, attitudes, and self-efficacy on measures related to the evaluation's research questions. The pretest surveys also collected demographic information. After completing the pretest, parents in the experimental group received the prototype of the parent component, namely, the parent's guide, with the instructions to read it. The parents in the control group received no intervention. One week later, both groups of parents took online post-test surveys, which were nearly identical to the pretests, though they excluded the demographic questions and, for those in the experimental group, included questions on their opinions of the parent component. Once we completed the data collection, we cleaned the data and analyzed them using statistical procedures in STATA.

## Findings

### **Parents who were exposed to Project PENCIL's parent component showed moderate knowledge gains on educational services for CIL.**

We asked several questions to ascertain the knowledge of parents on educational service issues for CIL, including a school's responsibility to identify CIL in need of educational services, mechanisms through which a parent can request educational services for CIL, effective teaching strategies for CIL in classroom settings, and useful practice techniques for promoting effective self-advocacy for CIL. On several questions, compared with parents in the control group, those in the experimental group showed greater but insignificant changes in knowledge, meaning that the findings could be due to factors other than exposure to the parent component. However, parents who were exposed to the parent component did indeed show significantly increased knowledge about a school's ability to deny an evaluation request for educational supports and accommodations and what to do when CIL's needs are not met in the classroom.

**Parents who were exposed to Project PENCIL’s parent component showed minimal changes in their attitudes toward seeking and obtaining educational services.**

Parents in the experimental and control groups reported very positive attitudes about securing educational services for CIL on nearly every measure at pre-test. These positive attitudinal responses prior to the experimental group’s exposure to the parent component severely limited the possibility of their wide-scale attitudinal improvements. Still, those who were exposed to the parent component did demonstrate a statistically significant increase, compared with non-exposed parents, on one question, namely, their positivism related to the application process for educational services.

**Like changes in knowledge, parents who were exposed to the parent component showed generally moderate increases in self-efficacy, but the results are mixed.**

To measure parents’ change in self-efficacy, we asked them the same ten questions at pretest and post-test about their belief and confidence that they could perform difficult tasks related to understanding, securing, and managing educational services for their CIL. The questions centered on the topics of service application processes; information to share with the school about the CIL’s chronic illness; research on specific educational supports and accommodations to help CIL succeed academically and socially; and managing school administrators, educational teams, and classroom teachers. On most questions, parents who were exposed to the parent component showed greater, positive changes in self-efficacy than parents who did not review the parent component, though the increases, while encouraging, were statistically insignificant. However, experimental group participants did indeed demonstrate statistically significant improvements on their belief that they could effectively research specific educational supports and accommodations for their CIL.

## Discussion

These evaluation results present a mixed picture of the effectiveness of the prototype of Project PENCIL to improve parents’ knowledge, attitudes, and self-efficacy on securing and managing educational services for CIL. On the one hand, those who were exposed to the parent component experienced moderate though typically insignificant changes in knowledge and self-efficacy. With respect to knowledge gains, parents tended to show the sharpest increases on questions that focused on alarming topics, such as the denial of educational services at the school or classroom level. The questions on potentially less

alarming though more tactical topics showed less dramatic knowledge change. With respect to self-efficacy, only one question – on the topic of research – showed a statistically significant increase, compared with the control group, though most parents in the experimental group showed incremental and positive increases in self-efficacy after their exposure to the parental component.

On the other hand, changes in parents’ attitudes were substantially more muted, though they relate in part to the very high positive attitudes among parents in both groups at pre-test. One may hypothesize that there is a direct and positive relationship between a parent’s knowledge of educational service issues for CIL and their attitudes toward obtaining and managing them, but these evaluation results suggest no such relationship. In other words, even those parents who had relatively poor understandings of how to seek and manage educational services for CIL still had very high positive attitudes about them at both pre-test and post-test. The implication of this finding cuts both ways. On the up side, parents’ positive attitudes towards educational services for CIL may heighten their resolve to seek and manage them, even in the absence of knowledge. On the down side, parents’ positive attitudes without the requisite knowledge of CIL educational service issues may diminish their likelihood of effectively obtaining and managing services.

In the end, these mixed results may reflect the nature of prototypical design, rather than its content. Indeed, because the parent component included only print materials, but not the interactive and video-based aspects of the planned final version of Project PENCIL, parents who excel at visual or auditory learning may fare better with the content of the parent component in its completed state.

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