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Parental Advocacy Styles for Special Education Students During the Transition to Adulthood

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Abstract

In an ethnographic study of planning for the transition to adulthood, we explored parental advocacy styles in special education settings for youth and young adults with chronic health conditions and developmental disabilities. Of 61 parents, 43 were satisfied with outcomes in negotiations for school services for their children. We identified three parental advocacy styles for these parents: (a) high profile parents who insisted on specific, wide-ranging services for their children that often resulted in conflict with educators; (b) strategic parents who negotiated for selected goals and were willing to compromise, and (c) grateful gratifier parents who formed close relationships with educators and trusted them to make appropriate decisions. Eighteen parents were overwhelmed, burned out, or unfocused, and generally dissatisfied with outcomes of educational planning meetings. Professional efforts to enhance parental advocacy can target development of skills and strategies that have worked for successful negotiators.

Keywords

adolescents/youth; children; illness and disease; disability; developmental; ethnography; parenting; symbolic interactionism

The transition to adulthood is an important developmental process in which teens and young adults assume responsibility for self-care, decision-making, and future planning (Kirk, 2008). For youth who have both developmental disabilities and chronic health conditions, the transition to adulthood is uniquely challenging because many will require ongoing support to maximize health, independence, and quality of life (Rehm, Fuentes-Afflick, Fisher & Chesla, 2012). Because of the complexity of the transition process for this group of young people, and to better understand the issues faced by parents, educators, and health care providers, we undertook an ethnographic study, in the symbolic interaction tradition, of planning for the transition to adulthood (Becker, 1998; Blumer, 1969; Schwandt, 2000). The purpose of this article is to present findings about advocacy styles of parents of youth who had both chronic medical conditions and developmental disabilities as they negotiated with school officials. Parents negotiated for goods, services, accommodations, and school

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placements to promote their child's health and education. Advocacy styles and negotiating tactics are described for parents who were satisfied with outcomes of negotiations for school services and those who were dissatisfied. Our study was based on the premise that parental advocacy styles influence communication with education and health professionals and impact the likelihood of success in achieving desired transition outcomes. The term "youth" will be used to encompass the adolescents and young adults (age 14–26) who are the focus of this article. This term is recognized by the World Health Organization (WHO) and widely used in transition literature (WHO, 1989).

Background

In 2009–2010, there were more than 11 million children in the United States with special health care needs, including 1.3 million adolescents (age 12–17) who had a chronic health condition and developmental, emotional, or behavioral needs for which they received special education services (Child and Adolescent Health Measurement Initiative [CAHMI], 2012). Children with both a physical health condition and a need for special education used significantly more health services (\$3,891/year) than children who only had a physical health condition (\$1,426/year), or those who had no chronic conditions and were not enrolled in special education (\$644/year) (Sices, Harman, & Kelleher, 2007). In a national survey only 29% of adolescents with both health and developmental needs were receiving the full spectrum of transition services recommended by the Maternal Child Health Bureau (CAHMI, 2012).

Data collection and analysis in this study was informed by Transition Theory, an emerging middle-range theory encompassing transitions in health and development (Meleis, 2010; Schumacher & Meleis, 1994). Within Transition Theory it is recognized that transitions profoundly affect health and occur in multiple realms, often simultaneously. Confrontations of different or unmet expectations are described between key players in the transition. There is flow and movement across time, and critical points and events affect transitions. Facilitators and inhibitors of transition arise from personal realms (e.g., meanings of events, cultural beliefs and attitudes, socioeconomic status), community realms (e.g., available resources and support), and societal realms (e.g., stigma, marginalization).

Within the Individuals with Disabilities Education Act (IDEA) (Cortiella, 2009) the Individual Education Program (IEP) is described as the central mechanism for decision-making for children and youth in special education. Educators are legally required to include both parents and youth in IEP meetings. These meetings take place at least once a year, but can occur more often at the request of parents or educators. By age 16 years, meaningful goals and services are mandated for the transition from high school to post-high school life.

Investigators in previous studies of parental satisfaction with special education services have reported mixed results. In small studies that included ethnically diverse samples, parents often had positive relationships with individual teachers and reported that they understood special education services (Fish, 2008; Rehm, 2002a; Rehm & Rohr, 2002b) even if they struggled to obtain desired support. Parents have described at least a moderate level of involvement and satisfaction with the IEP process (Hughes, Valle-Riestra, & Arguelles,

2008; Spann, Kohler, & Soenksen, 2003). Other researchers reported parental dissatisfaction with school services for children with chronic conditions that sometimes resulted in conflict. For example, Garwick, Patterson, Bennett, and Blum (1998) interviewed parents of 124 children and pre-adolescents with chronic health conditions in Minneapolis and Seattle. Parents recalled 58 specific incidents of unsupportive interactions with teachers, administrators, and school nurses. These included instances of inadequate provision of services, insensitivity or lack of recognition of the child's needs, and inadequate knowledge or understanding of the child's condition. Other researchers have reported that parents and educators held discrepant views of the child (Kliebenstein & Broome, 2000), and that there was poor parental-educator communication and devaluation of parents' expertise (Lake & Billingsley, 2000). Parents of children with Autism Spectrum Disorders and other special needs perceived that trust between parents and education professionals was a key factor in determining the extent of their engagement in school (Angell, Stoner, & Shelden, 2009). Parental trust was related to family, teacher, and school characteristics, and these characteristics influenced parents' perceptions of educators' levels of caring, communication, personal knowledge of individual children, and the overall school climate.

Parental advocacy has been found to serve three primary functions: (a) advocating for services to meet the child's needs; (b) acting as an expert on their own child; and (c) protecting the child from incompetent or uninformed professionals (Lutenbacher, Karp, Ajero, Howe, & Williams, 2005). Trainor (2008, 2010) analyzed the effect of parents' cultural and social capital on their participation in special education planning and negotiations. Based on focus groups and individual interviews of European American, African American, Latino, and Native American Indian parents of children with disabilities living in a midwestern state, Trainor concluded that European American parents drew on forms of personal capital such as education, use of information, and financial resources. She reported that parents with varying levels of acquired capital drew heavily on social networks to learn to negotiate school systems and also determined that parents of color were often disadvantaged in negotiations because school personnel were less likely to share parents' values and assessments of the unique needs of their children.

Parental involvement, in general, has been shown to improve academic achievement for children from ethnic/racial minority groups (Barton, Drake, Perez, St Louis, & George, 2004; Carreon, Drake, & Barton, 2005; Jaynes, 2003). However, several authors have reported that parents from minority ethnic and racial populations faced distinct challenges in working with the special education system, particularly because their expectations were often different from those of educators. Kalyanpur, Harry, & Skrtic (2000) posited that parents who have a group-oriented perspective, rather than an individual-oriented perspective, might have different expectations for parental advocacy in special education meetings. For example, they contrasted the collectivist goals articulated by a group of Chinese immigrant parents with educators' individual-oriented goals and expectations. The authors posited that parents who expect professionals to use their expertise to make appropriate decisions for children might be puzzled by an expectation of parental participation in decision-making. Chinese American families in another urban district were described as having low participation in IEPs because of language and cultural barriers (Lo, 2008). In another study, African American parents in a large urban school district were

initially actively involved in an early education program. They became disillusioned when their expectations were not met and participation decreased (Harry, Allen, & McLaughlin, 1995). In a study of Latina mothers in the rural Southwest, the women described a desire to be involved in their child's IEP but felt silenced and disrespected during meetings (Salas, 2004). In a review of 399 IEP documents from two large, urban school districts in the western United States, federal requirements for transition planning were often unmet, but there was no systematic relationship between the quality of the transition plan and race/ethnicity of students (Powers et al., 2005).

A few studies have explored the process of parental involvement in special education across the age and developmental spectrum, as children moved from pre-school through high school (e.g., Angell, et al., 2009; Spann, et al., 2003). Children with serious medical conditions have occasionally been the focus of previous studies (e.g., Anderson, 2009; Garwick, et al., 1998; Kliebenstein & Broome, 2000). However, no studies have addressed the unique transition issues that affect youth in special education, who have both chronic health and developmental issues. We will focus on negotiation and advocacy styles of parents for this group of students.

Design and Methods

This study was based on an interpretive/constructivist paradigm in the symbolic interaction (SI) tradition (Becker, 1998; Blumer, 1969; Schwandt, 2000). The purpose of scientific inquiry in this tradition is to understand everyday life from the point of view of those who live it. Reality is assumed to be situated, relative, and changeable as understanding improves and conditions change. Social and self-reflective processes result in personal and group meanings that lead to actions and decisions for individuals and families. Knowledge and the findings of research studies are considered transactional, i.e., jointly created by investigator and informant, and require the investigator to actively enter into the world of people being studied (Becker; Fine, 1995; Schwandt).

The current analysis is from an ethnographic study focused on planning for the transition from adolescence to adulthood for youth with chronic health and developmental diagnoses. Aims were to explore how parents worked with health and school systems and the impact of planning for transition on families. The study was approved by the Committee on Human Research at the University of California, San Francisco as well as study participants' school authorities. Informed consent, assent, or surrogate consent was given for youth, parents, and professionals, in accordance with approved procedures.

Sample

We focused on adolescents and young adults who had both a chronic physical health condition and a developmental (usually intellectual) disability. The chronic health conditions included congenital heart disease, diabetes, genetic conditions, and seizures. All youth required ongoing monitoring for health concerns and most were receiving treatment in the form of medications, assistive technology, and/or speech, physical or occupational therapy. We recruited the participants from community and health care settings in urban, suburban and rural areas in Northern California. We recruited 64 youth who were 14–26 years at the

time of recruitment. Youth up to 21 years of age (N=46) lived at home with their families. Young adults in the 22–26 year old group (N=18) participated in a variety of post-school activities and lived in either family or community-based settings. All youth were currently enrolled or had previously been enrolled in special education services. About half of the youth were verbal, though fewer were able to articulate their reflections on their own experiences. Parents were asked to state racial or ethnic categories for themselves and their children and 43% of youth and 41% of parents were categorized as ethnic/racial minorities. The 61 parents in this analysis self-identified as African American or Black, 9; Asian, 12; Latino, 4; and White, 36. Fifty-five youth received partial or complete government support for health insurance, and 34 also had private health insurance.

Data Collection

Ethnographic methods were used for all study activities. The study was conducted from 2007–2011. For this project we analyzed data from 116 interviews with parents (61 first interviews and 55 second interviews), and 36 interviews with the teachers and others who worked at the youths' schools, such as therapists. Parents were interviewed twice, at enrollment in the study and approximately 6 months later. The purpose of second interviews was to follow-up issues identified in first interviews with more in-depth discussion, and to discuss preliminary data analysis with participants. Questions for second interviews were formulated after preliminary research team analysis of initial interviews. We used investigator-designed tools and field notes to collect observation data during 41 IEP meetings for youth who were enrolled in school during the study. Youth attended middle schools, high schools, and transition programs scattered through 7 counties in Northern California, including large, urban, unified school districts, and smaller suburban and rural districts.

We developed interview guides based on topics and conditions identified in Meleis's Transition Theory (Meleis, 2010), and modified them to incorporate issues raised by participants. We included open-ended questions and semi-structured probes. We asked parents about their level of satisfaction with school-related negotiations for services and to describe their negotiation strategies. Parents and teachers were asked to describe educational and school-related goals and strategies to achieve them for individual youth. We also asked about general experiences and impressions about negotiating for services at school.

Data Analysis

We analyzed data in a multi-step procedure that included construction of an overall family summary that was periodically updated as data collection and analysis proceeded. At least 2 members of the research team initially coded each interview transcript. We conducted a second level of focused recoding, as we identified important topics and concepts. Preliminary findings were discussed with participants during follow-up interviews or observations. During the analytic phase of the project, the principle investigator, project director, and research associate met weekly. The entire research team met every month to review findings and reach consensus on data interpretation. We achieved data saturation for findings reported in this article.

Based on questions about satisfaction with outcomes of school-based negotiations we classified parents as satisfied with school negotiations (N=43) or dissatisfied with negotiations (N=18). We then reanalyzed data about negotiations for the satisfied and dissatisfied participants. At this point we looked for types of advocacy strategies, areas of agreement and conflict with school personnel, and patterns of interactions described by parents and educators. After the categories described in this article were identified, three members of the research team independently placed parents into the categories and then discussed their assignments and reached consensus on placements.

Findings

By the time that our participants reached adolescence, their parents had accrued years of experience as advocates within the school system. Most parents were strong advocates for their children but we found that parents used a variety of negotiation styles, had varying goals, and achieved variable outcomes. Parents reported that daily care of their adolescent/young adult was very demanding, which created ongoing challenges. One parent explained:

You start out in such a different place than you do when you have a healthy baby, and you have to learn so much, and at each stage you don't know what even to ask for. It's just this huge bundle of stuff that has to happen for some kind of success to occur for a kid like [mine] at each transition.

The Role of Social and Material Resources

Nearly two-thirds of parents had some college or had completed at least a Bachelor's degree. Educational levels were highest for White parents (most had college degrees). A majority of African American and Asian parents had some college education. Latino parents had the lowest educational attainment. Both parents and education professionals recognized that more affluent families had advantages when negotiating with school districts. The factors that parents identified as advantages were English language skills, financial security, knowledge of systems and organizations, time for advocacy, social position, and professional-level negotiation skills (e.g., lawyers, teachers). A parent described her own advantages, "The more private resources we added to the mix, the more advancements he's made, obviously. So we're very, very fortunate to have resources, and being in a socioeconomic status to be able to do that." A teacher explained that administrators sometimes took advantage of parents who had fewer resources, "We're a district where the parents come from other countries and may not know what their rights are, and I think the district plays that card like, 'Oh well, they're not aware' ... and they're just kept in the dark."

We interviewed parents who had multiple life demands, lower levels of education, and few material resources who were nonetheless very successful advocates for their children. Single parents who lacked family support, parents with financial constraints, serious health conditions, or multiple caregiving responsibilities were sometimes limited in their ability to interact with the school system. However, we found that they were successful when they were persistently engaged with their child's school, formed effective partnerships with teachers and other school personnel, and developed advocacy skills that matched parents

from more privileged backgrounds. Two poignant examples were African American family care providers who themselves had serious chronic health conditions. Both received Social Security Disability Insurance, lived in public housing, and had limited family support. These two caregivers, a custodial brother and a mother, successfully advocated with an urban school district to provide needed services. Their strategies included persistent attendance at planning meetings, self-education about legal rights and available programs, clearly defined goals, and vigilant relationships with educators, that allowed for follow-up to resolve questions or disagreements as they arose.

Most parents who were satisfied with the negotiated outcomes for their child's educational services adopted one of three advocacy styles: (a) high profile parents, who took an active and demanding stance with educators and sought the "best" services available for their child, (b) strategic parents, who "picked their battles" and carefully researched and selected those services for which to advocate, and (c) grateful gratifier parents, who formed mutually respectful and satisfying relationships with school personnel. Another group of parents were dissatisfied with school services, resulting in frustration for both the parents and school personnel. These parents often faced multiple demands, were single parents, and were exhausted or burned out, though they continued to be committed to their children's care.

High Profile Parents

Parents from 11 (1 African American, 1 Latino, and 9 White) families were labeled "high profile" and "bulldogs" by teachers and school officials. High profile parents were well known within the educational systems. Educators considered these parents insistent and demanding as they sought extensive services through multiple channels until their objectives were met. School personnel believed these parents felt entitled to the "best" for their child, more than the "appropriate" education mandated in the IDEA law. High profile parents considered their requests as essential and reasonable and viewed the teachers or principals as inept or withholding if requests for services were not readily granted. One example is the mother of a 21 year old young man, who said "after a year of volunteering [in his school] it became clear to me that the district had the money to send him to the private school. You just had to put the pressure on them to do it." She hired a lawyer and the school district paid "\$100,000" for her son's tuition and transportation to a private school in another town. Another parent described how she learned to be effective when demanding services:

Most of my friends now are parents of kids with special needs, so lots of networking going on. How to get through IEPs so you get what you need for your kid, because there's not enough money. You have to fight really, really hard and you have to know how to fight.

Some high profile parents described a history of animosity between parents and school administrators based on denial or limitation of services. They described escalation of this animosity through the years because school districts generally supported fewer therapeutic and specialized services, such as speech therapy, as youth matured and school personnel determined that the youth was unlikely to make additional progress as a result of these services. Parents, in contrast, hoped that their child would continue to progress. One mother described her daughter's situation:

As she got older I had to really fight. Of course their resources are slim, and yadda yadda yadda. The words out of the OT's mouth were "She hasn't made much progress. We didn't get anywhere, so it's basically when we get to this age, there's not much we can do." That's the attitude I got, which is completely wrong I think. Not just wrong morally and ethically, but wrong. If you think of people that are developmentally delayed, some of these people, with continued work, do learn, just they're really, really slow.

High profile parents were predominately White and well educated, with 6 of 11 parents in this category having a college or post-graduate degree. Families lived in both urban and rural settings. They made themselves visible in school and school-related activities such as community advisory boards, as school volunteers, and as paid advocates or staff in family support organizations. According to school personnel, parents were sometimes successful negotiators because school districts were intimidated by threats or fears of prolonged and costly legal proceedings and acceded to demands rather than continue in conflict.

A pervasive culture of advocacy arose from parents' interpretations of broad and complex laws, regulations, court judgments and entitlements, and this information motivated parents to pursue what they perceived they were due. High profile parents were very confident that they were the best judges of what would help their child most. The mother of a 15 year old said, "But I do know and I read a lot. I ask questions and I know what my child needs." Not all parents were clear or accurate in their understandings, but they often sought support from specialized attorneys and disability rights organizations. A transition teacher described this culture of advocacy:

[There is a] new breed of parents, White and middle or upper middle class, who have rights, are entitled. Usually in the past I had no families like this. It was mostly minority families who were just really grateful to have a place for their kid to go. That's kind of the mentality, "It's there, I want it. And I get to have it and I am gonna get it and if you say no, we are going to call up the lawyer, I am going to call up the advocate, and I am going to go to the Board of Ed." So, then everybody says "Okay, just give it to them."

School professionals perceived that parents who made numerous demands were fueled by guilt, grief or ambition. A teacher explained, "These families have high functioning kids who go to Yale and Stanford, and they're going to apply that same kind of force that they apply to their own lives to their low functioning child." In other cases, high profile parents pursued non-traditional therapies such as chelation, dietary and chemical therapies, and costly behavioral intervention programs that have little scientific evidence of efficacy. A psychologist who worked with parents and schools said that some parents advocated for devices or specialized services that have little or no objective merit after they learn of such interventions from friends, online sources, workshops or conferences. A speech and language therapist explained her impression of high profile parents:

Some people come in with a vision that is completely impossible to manifest, and they still haven't let go of the grief that their child is not going to excel or that their child isn't going to do X, Y, and Z. So then, and this is more the high powered

litigious families I'm talking about, they go through hating the district because this teacher didn't cure my child, and it's always the district's fault.

Advocacy and negotiation styles were not static, and parents discussed the evolutions that they experienced across the years as they determined what style worked for them. For example a mother explained her style of attempting to deal with individual teachers, but moving on to the principal if necessary:

It developed over time. At first I was kind of confrontational I guess. You just have to do it, you know? And then I kind of softened my approach over the years, but the bottom line always was that it's the law and you have to do it, and they did make me angry. But I would try to go in and talk to the teacher personally and speak to them reasonably, and then if that didn't work, then I would talk to the principal, and then the principal in every case was fine, so we didn't have too much trouble there.

Strategic Parents

In contrast to high profile parents, who often antagonized school personnel, the strategic parents (N=14, 2 African American and 12 White) were deliberative and tried to avoid direct conflict. These parents chose specific goals, were diligent, non-confrontational, yet persistent. The father of a 17 year old explained:

They've been trying to cut speech therapy, and we push back, and we get more, and they push back and we agree to this if they provide that, and it goes back and forth. We've taken a cooperative model rather than a confrontational model.

The mother of a 14 year old discussed one strategy, which notified school personnel that she was a serious advocate, yet avoided direct confrontation:

I've just learned that you catch more flies with honey; but the very first IEP, I had my husband come and dress like a lawyer and not say anything. I didn't want him to say a word because he wouldn't know what he was talking about. He's come again but we've never played that game again, even once, and I never had an issue.

Strategic parents picked their battles. One mother explained, "I think as a parent you have to really be willing to compromise and step back a little bit, and fight for the key important things but sort of let the rest of it[go], just be okay with it." Strategic parents consulted with professionals in the field (e.g., medical specialists, educational lawyers, behavioral psychologists) and clients' rights organizations. These parents held others accountable and followed-through to ensure that negotiated agreements resulted in appropriate action. This subgroup of families complied with legal deadlines, was persistent and engaged, and set a tone of expectation for compliance from school districts.

Although these parents preferred to compromise with school officials, they were willing to threaten and take legal action if other attempts for recourse had failed. Formal action was not undertaken lightly. Parents prepared by consulting with attorneys, learned about court decisions that were similar to their own situation, and used legal, rather than lay, terminology with district authorities. This presentation of self extended to IEP meetings, where parents positioned themselves as equals with decision-makers while adopting a tone

of partnership and compromise. They knew how and when to escalate (or de-escalate) advocacy efforts as situations changed, and many maintained close relationships with leaders of disability rights organizations.

As a group, strategic parents were well educated, with 8 out of 14 having college or postgraduate degrees. Strategic parents were primarily White, had professional training, and many had worked in teaching, law, engineering or business, and sometimes left their jobs to care for their child. Most were married. Typically, the father worked outside the home while the mother oversaw the home and cared for the children. The mother's role included gathering information and managing its use. They built on a broad knowledge base and used a range of tactical maneuvers, including prioritizing their preferences among specific goods, specialized services and accommodations. With economic and social resources, parents proceeded with intuitive as well as deliberate approaches to action. Examples of advocacy activities of strategic parents included organizing a group of parents to pressure the district to reorganize the transition program, playing "good cop – bad cop" in IEP meetings, and taking their youth to testify before the school board. Parents educated themselves about relevant issues and also sought coaching, or surrounded themselves with strong advocates. The mother of an 18 year old told the following story:

My [friend] had me reading a law book on special ed. I know how to access that now. Anything that you need to know, I know where to go and how to write letters saying, "According to the special education law code of 2007, Article da-da, Paragraph da-da, kids with da-da-da should have da-da-da." I tell them [my child] needs this, and why.

Strategic parents knew that supportive services and equipment were costly and difficult to obtain so they used phrases such as "educationally related" in their requests. This language is included within the IDEA law to illustrate the types of health services that must be paid for by school districts, including nursing care, behavioral health, and other therapies (Cortiella, 2009). Positive, long-standing and personal relationships with local authorities and school officials were particularly useful to strategic parents. They also acknowledged that their resources, such as facility in English, time, financial security, and social ease helped them access services.

Grateful Gratifier Parents

Grateful gratifier parents (N=18, 2 African American, 8 Asian, 1 Latino, and 7 White) engendered good will by appealing to educators' desire to make a difference in students' lives and being appreciative of assistance offered. In turn, professionals perceived that these parents were particularly deserving of their assistance because they were properly involved with their child (not too protective nor too removed), did their best in prolonged and trying circumstances, held realistic assessments of the youth's strengths and disabilities, and made appropriate and reasonable requests. The teacher of a 14 year old said:

(Her parents) make it really easy, she has good experiences, her mother is happy. There is a personal thing about it too. Some other families didn't embrace the student's disability. Her family seems to totally accept this, celebrate it even, like this is who she is. Her mom always appears to be up and happy. I know she

probably isn't, but she knows that it's important to communicate that to [her daughter] and those who work with her.

Grateful gratifier parents considered educators as trustworthy and informed partners, who were committed to enhancing their child's potential. A mother said, "The current special ed director used to be the middle school coordinator, and I have a very, very good relationship with her, and she has really been good about communication and meeting needs." More than parents who used other advocacy styles, some grateful gratifier families maintained a personal relationship with teachers across several years. One father of a 22 year old said "Over the years, [a specific teacher] advocated for [my son]. She saw what he could be if he only was given a little help. Sometimes we think it's not even her job anymore, but she still calls us." Teachers felt their efforts were rewarded by a youth's progress toward specific goals and by parents' commitment and follow-through with teacher recommendations. A former teacher of a now 25 year old young man described the progress that he had made:

So when I think of this scared little 17 year old, to a young man who's going to school, who lives in his own apartment, who manages his own money, who's managing his diminishing vision. I just see that everything that I would hope for a student, he's done. There might be barriers but I don't see him ever stopping with his dreams.

Grateful gratifier parents came from every racial/ethnic group, including first generation Asian and Latino immigrants, African Americans, and Whites. Grateful gratifiers came from a variety of educational and occupational backgrounds, and included those with high and low financial and social resources. They lived in urban, suburban and small towns, in wealthy as well as financially-strapped school districts. The reciprocal respect and attraction of parents and teachers was based on their common values, beliefs, and actions that were aligned with mutual expectations, and led to agreement on parenting and long-term goals. Teachers were also drawn to parents who understood and accepted the child's disability in a manner that was similar to the professionals, and therefore accepted school services that educators considered appropriate. Parents were especially drawn to teachers and personnel they felt had gone out of their way to "show them the ropes" and helped them achieve meaningful supports for their youth. For example, a mother remembered the teacher who, 14 years earlier, had created a behavioral intervention plan for her daughter and encouraged and taught her how to successfully request a non-public school.

Unsuccessful Negotiations

Eighteen parents (4 African American, 4 Asian, 2 Latino, and 8 White) did not receive requested services for their child's educational experiences. This group of parents was not successful in negotiations for wide-ranging reasons. These included lack of knowledge about available or appropriate services, or lack of skills necessary to challenge denials of requests from school districts. Some had personal or culturally-based beliefs about authority or maintaining harmony in life's dealings. These parents came from every racial/ethnic group. Only one married couple fell into this category; the others were single, widowed, or divorced mothers. Many single mothers noted that confronting day-to-day challenges of caring for a child took precedence over long-term planning:

I've never been very good at thinking way ahead and doing all my research ahead of time. You're so busy dealing with the day. [My child] still needs to be fed and changed and loved, and all of those things need to happen in addition to trying to think ahead. So a lot of times thinking ahead, that just didn't occur.

Parents were sometimes ineffective in negotiations because they were overwhelmed by their personal situation and competing priorities. A mother born in Hong Kong explained:

When she born, my family don't support me. And, it's OK, it's OK with me. I take depression medicine. It's not because of [my daughter], because I have breast cancer. So I have to take care of myself with different ways, medicine, exercise, be happy, enjoy life.

Although some parents in other categories also had multiple stressors, they were able to draw upon personal resources to successfully advocate for desired services and goods. The parents who did not achieve their requests were seen by teachers as poorly focused and unable to prioritize their child's education above more pressing personal concerns such as emotional or physical health challenges, financial pressures, and legal difficulties. These issues were often manifested to teachers as a lack of parental follow-through and dropped responsibility for decisions and plans. A teacher described the family of a 15 year old, in which the parents were going through a divorce:

I think being the overwhelmed family is a big factor. They really, really want the best for him and really, really want to try, but they're not following through on things they say they'll follow through on, which makes it very hard here, harder than it would be otherwise.

Successful advocates in other categories appealed adverse decisions and sought redress. However, parents in this less successful group did not publically disagree with school officials or escalate their actions in response to decisions made about their child's education. Instead, some avoided direct confrontation and expressed their dissatisfactions to sympathetic others without decisional authority. Other parents were more tolerant of decisions, and accepted whatever special education services were voluntarily provided by the school.

Some mothers enlisted others to assist them, but failed to clarify an action plan. One mother brought a friend, who also was the mother of a special education student, to an IEP meeting. The mother questioned her son's high school teacher about providing a sufficiently challenging academic experience but did not persist or suggest an alternative plan. After the meeting, the mother was annoyed at her friend, and asked why the friend did not speak up. In another example, the mother of an 18 year old said, "It's a delicate balance. I never wanted to be one of those strident, complaining special ed parents." This mother was troubled with her son's school services, and ultimately removed him from school, rather than confront school officials.

Parents in this group whose requests were denied attended their youth's IEPs, but left the meeting disgruntled and some refused to sign the IEP plan. Their unsuccessful attempts to attain desired goals commonly lacked specific objectives or ways to achieve them. For

example, this subgroup of parents voiced general complaints rather than explicit requests, did not access proper channels of appeal, or mobilized too late in the youth's educational trajectory. In addition, teachers critiqued these parents as having goals that were unrealistic, such as one father who wanted his son to apply to West Point Military Academy despite his son's 4th grade reading level. Tense and protracted IEPs occasionally resulted when meetings were focused on one contentious issue, and neither parents nor school officials were able to readily compromise. In one such meeting, parents disagreed with several teachers and counselors who recommended a program after high school and psychological counseling for a young man they believed was depressed. The parents acceded to their son's wishes and refused both services. Afterwards, the teacher surmised that the long history of disputes between this family and district officials colored the discussion so that parents rejected any proposal from the school. A long history of conflict with school personnel sometimes resulted in parental burnout. A mother explained:

As a parent of a kid like [my son] you're constantly fighting, fighting for every goddamn thing. And I think you just get to a place, I've been doing this for 17 years, where it's like, I think I'm just chilling. I'm just like okay. I can't do it.

Discussion

In this study of parents of adolescents and young adults with chronic health and developmental conditions, we identified a variety of parental advocacy styles. Our findings demonstrated that parents and educators were highly influenced by the parents' personal and professional skills. For example, strategic parents utilized careful research, negotiation skills, and willingness to compromise to avoid conflict with educators, whom they considered peers and equals. Grateful gratifier parents were also respectful, but in contrast to other successful negotiators, ceded expertise to educators, who reciprocated with on-going assistance. The demanding style of high profile parents more commonly resulted in conflict between parents and educators. Nevertheless, demands and intimidation often did lead parents in this group to accomplish their goals, as educators sought to avoid legal entanglements and protracted confrontation. Successful negotiation strategies identified in earlier work with younger children were also identified with this older population of youth including learning about rights and responsibilities, focusing on children's individual needs, and being persistent in the face of systemic barriers (Rehm, 2002a; Rehm & Rohr, 2002b).

Our findings concentrated on advocacy styles, shedding new light and additional detail to extend earlier studies of parental roles and resources. Supporting Trainor's (2010) analysis of the role of social and cultural capital in special education settings, we also found that parents who were satisfied with IEP outcomes tended to draw heavily upon skills in acquiring information, forming relationships with professionals and other parents, and negotiating complex legal rights and bureaucratic systems. Our findings extended Trainor's analysis by identifying the skills that parents of color were able to use to meet their goals. For example, parents who were grateful gratifiers included parents from all ethnic groups who built trust and respect with professionals using social skills to create mutually satisfying relationships. We learned that in maneuvering as advocates for educational planning nearly all parents were monitors and supporters (Stoner et al., 2006). Most parents incorporated

roles described by Lutenbacher et al. (2005) as expert and guardian, whereas “fighters” (Lutenbacher et al.) were most likely to be high profile parents, and strategic parents were expert negotiators (Stoner et al.). In our study, the active high profile and strategic advocacy styles, as well as the more subtle, less openly strategic, grateful gratifiers achieved their goals. Grateful gratifier and strategic parents developed high levels of trust, as found by Angell et al.(2009); however, high profile parents did not trust the system to provide for their children and were likely to use confrontation and demanding tactics.

Parents of every ethnic/racial group and educational level were among both those who achieved desired goals in negotiations and those who did not. More parents of color and single mothers were unable to achieve desired outcomes. Our findings indicate that race/ethnicity and socio-economic status are influential, but not determinative, factors in the success of advocacy efforts. Parents who did not achieve their goals were no less dedicated to their children’s ongoing care and support than more successful advocates. As in previously published findings, parents participating in this study universally expressed commitment to the long term well-being of their children during and after the transition to adulthood (Rehm et al., 2012). Our findings indicate that advocacy efforts failed because parents lacked information about appropriate services or how to appeal denials of requests for school services, or because they were not persistent in trying multiple strategies to achieve desired outcomes. These shortcomings are potentially amenable to specific professional support efforts through provision of information and teaching advocacy strategies. Challenges inherent in facing multiple competing life demands are more difficult to address.

Implications for Educators and Health Care Providers

The variety of advocacy styles and outcomes seen offer a foundation for improving relationships and effective negotiations between parents and professionals. This study focused on advocacy in school settings, but it is likely that successful advocacy strategies would also work well in health care settings. For example, successful strategies, such as identifying specific goals, researching appropriate and available resources, and following through on meeting deadlines and other negotiated obligations, could be fostered in all parents. The ability of parents from a multiple socio-economic, educational, and cultural groups to achieve satisfaction with IEP outcomes attests to the possibilities for successful advocacy of a wide variety of families. Professionals might find it useful to adopt goals for parental education such as: (a) expressing explicit respect and acknowledgement to parents who are coping with challenging lives, recognizing their many life demands (Wright, Watson, & Bell, 1996); (b) engaging with parents prior to meetings to write a mutually agreeable transition program, which includes specific health and education concerns; (c) assisting parents to understand the patterns of progress of their children, including evidence that supports or refutes the likelihood of additional progress and the effectiveness of particular educational supports; (d) working with parents to identify their top objectives for their child, and offering support for those, including potentially trading away support for lesser priorities to support those things most desired; (e) conducting one on one meetings with overwhelmed or burned out parents to identify one or two goals that parents can support, even if they are not the originators of specific actions to be taken; and (f) offering

concrete suggestions for sources of additional information, including advocacy training, and soliciting the assistance of other professionals or community support organizations providing care and services for the youth.

Limitations

All participants in this study spoke English, and the experiences of parents and families with limited English language skills might be different. Although the overall sample was ethnically diverse, the numbers of participants in specific ethnic/racial categories was small. Similarly, our participants came from a wide range of educational and socio-economic strata, but were mostly well-educated and middle class. This type of heterogeneous study sample allowed us to describe commonalities between groups, but future research is needed with larger samples of particular subpopulations to be able to authoritatively describe differences between larger categories and variations within ethnic/racial groups.

Conclusion

Parents of youth with both health and developmental challenges have developed a variety of successful advocacy styles that allow them to accomplish their goals for negotiations within IEPs. In the current study, parents who were dissatisfied with IEP outcomes expressed being overwhelmed, exhausted or frustrated with the lack of support from school officials and the absence of meaningful programs. Parents of youth with chronic health and developmental conditions are particularly challenged to obtain specialized services for their children. Parents and professionals must work collaboratively to advocate for academic and health issues and to plan for the transition to a meaningful adulthood.

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References

- Anderson LS. Mothers of children with special health care needs: Documenting the experience of their children's care in the school setting. *Journal of School Nursing*. 2009; 25(5):342–351.10.1177/1059840509334146 [PubMed: 19383837]
- Angell ME, Stoner JB, Sheldon DL. Trust in education professionals: Perspectives of mothers of children with disabilities. *Remedial and Special Education*. 2009; 30(3):160–176.10.1177/0741932508315648
- Barton AC, Drake C, Perez JG, St Louis K, George M. Ecologies of parental engagement in urban education. *Educational Researcher*. 2004; 33(4):3–12.10.3102/0013189X033004003
- Becker, HS. The epistemology of qualitative research. In: Jessor, R.; Colby, A.; Shweder, RA., editors. *Ethnography and human development: Context and meaning in social inquiry*. Chicago: The University of Chicago Press; 1996. p. 53-72.
- Blumer, H. *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall; 1969.

- Carreon GP, Drake C, Barton AC. The importance of presence: Immigrant parents' school engagement experiences. *American Educational Research Journal*. 2005; 42(3):465–498.10.3102/00028312042003465
- Child and Adolescent Health Measurement Initiative: Data Resource Center for Child and Adolescent Health Web site. 2012. Retrieved from <http://www.cahmi.org>
- Cortiella, C. IDEA 2004: Improving transition planning and results. National Center for Learning Disabilities; 2009. <http://www.nclld.org/at-school/your-childs-rights/iep-aamp-504-plan/idea-2004-improving-transition-planning-and-results>
- Fine, GA. A second Chicago school? The development of a postwar American sociology. Chicago: University of Chicago Press; 1995.
- Fish WW. The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure*. 2008; 53(1):8–14.10.3200/PSFL.53.1.8-14
- Garwick AW, Patterson JM, Bennett FC, Blum RW. Parents' perceptions of helpful vs unhelpful types of support in managing the care of preadolescents with chronic conditions. *Archives of Pediatrics & Adolescent Medicine*. 1998; 152(7):665–671. [PubMed: 9667538]
- Harry B, Allen N, McLaughlin M. Communication versus compliance: African-American parents' involvement in special education. *Exceptional Children*. 1995; 61:364–377.
- Hughes MT, Valle-Riestra DM, Arguelles ME. The voices of Latino families raising children with special needs. *Journal of Latinos and Education*. 2008; 7(3):241–257.10.1080/15348430802100337
- Jeynes WH. A meta-analysis: The effects of parental involvement on minority children's academic achievement. *Education and Urban Society*. 2003; 35(2):202–218.10.1177/0013124502239392
- Kalyanpur M, Harry B, Skrtic T. Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education*. 2000; 47(2):119–136.10.1080/713671106
- Kirk S. Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development*. 2008; 34:567–575.10.1111/j.1365-2214.2008.00862.x
- Kliebenstein MA, Broome ME. School re-entry for the child with chronic illness: Parent and school personnel perceptions. *Pediatric Nursing*. 2000; 26(6):579–582. [PubMed: 12026357]
- Lake JF, Billingsley BS. An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education*. 2000; 21(4):240–251.10.1177/074193250002100407
- Lo L. Chinese families' level of participation and experiences in IEP meetings. *Preventing School Failure*. 2008; 53(1):21–27.
- Lutenbacher M, Karp S, Ajero G, Howe D, Williams M. Crossing community sectors: Challenges faced by families of children with special health care needs. *Journal of Family Nursing*. 2005; 11(2):162–182. [PubMed: 16287824]
- Meleis, AI. *Transitions theory: Middle-range and situation-specific theories in nursing, research and practice*. New York: Springer Publishing Company; 2010.
- Powers KM, Gil-Kashiwabara E, Geenen SJ, Powers L, Balandran J, Palmer C. Mandates and effective transition planning practices reflected in IEPs. *Career Development for Exceptional Individuals*. 2005; 28(1):47–59.10.1177/08857288050280010701
- Rehm RS. Creating a context of safety and achievement at school for children who are medically fragile/technology dependent. *Advances in Nursing Science*. 2002a; 24(3):71–84. [PubMed: 11890196]
- Rehm RS, Rohr JA. Parents', nurses', and educators' perceptions of risks and benefits of school attendance by children who are medically fragile/technology-dependent. *Journal of Pediatric Nursing*. 2002b; 17(5):345–353.10.1053/jpdn.2002.127174 [PubMed: 12395302]
- Rehm RS, Fuentes-Afflick E, Fisher LT, Chesla CA. Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *Advances in Nursing Science*. 2012; 35:E57–E72. [PubMed: 22869218]
- Salas L. Individualized educational plan (IEP) meetings and Mexican American parents: Let's talk about it. *Journal of Latinos and Education*. 2004; 3(3):181–192.10.1207/s1532771xjle0303_4

- Sices L, Harman JS, Kelleher KJ. Health-Care use and expenditures for children in special education with special health-care needs: Is dual classification a marker for high use? *Public Health Reports*. 2007; 122:531–540. [PubMed: 17639657]
- Schumacher KL, Meleis AI. Transitions: A central concept in nursing. *Image-- The Journal of Nursing Scholarship*. 1994; 26:119–127.10.1111/j.1547-5069.1994.tb00929.x [PubMed: 8063317]
- Schwandt, TA. Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. In: Denzin, NK.; Lincoln, YS., editors. *Handbook of qualitative research*. Thousand Oaks: Sage Publications; 2000. p. 189-214.
- Spann SJ, Kohler FW, Soenksen D. Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*. 2003; 18(4):228–237.10.1177/10883576030180040401
- Stoner JB, Angell ME. Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*. 2006; 21(3):177–189.10.1177/10883576060210030601
- Trainor AA. Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital. *Remedial and Special Education*. 2008; 42(3):148–162.10.1177/0741932508324401
- Trainor AA. Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education*. 2010; 41:245–63.10.1111/j.1548-1492.2010.01086.x
- World Health Organization (WHO). Document A42/Technical Discussions/2. Geneva: WHO; 1989. The health of youth.
- Wright, LM.; Watson, WL.; Bell, JM. *Beliefs: The heart of healing in families and illness*. New York: Basic Books; 1996.

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