The Intersection of Poverty & Autism Spectrum Disorder
A study of institutional and individual disparities in healthcare for autism

Anna Dorsett ’15

KEY WORDS
poverty, autism, autism spectrum disorder, ASD, therapy, treatment, applied behavior analysis, healthcare reform, insurance reform, mental health parity, discrimination, education, limitations
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Abstract

This paper explores several published articles that report on the intersections between poverty and autism spectrum disorder. Several authors state that access to care for this mental health issue is limited for disadvantaged families due to the high cost of care and the low incidence of insurance coverage, while others insinuate that more social causes are at fault: minority discrimination, lack of parental educational attainment, or geographical variations in resource availability. This paper examines research regarding potential contributions to variations in care among the disadvantaged, briefly proposes ideas for future research, and concludes with ideals for policy reform in response to this research, as well as an ethical argument regarding the topic’s public value.

Introduction

Many young children and their families experience great trepidation upon receiving a diagnosis of an autism spectrum disorder. This diagnosis is particularly strenuous for families in poverty, who may not have the appropriate knowledge or access to resources to care for their child’s needs. Autism spectrum disorder (ASD) is a developmental disability that can lead to significant communication and behavioral challenges in individuals of all ages. Some people with ASD need life-long assistance in daily activities; others are only minimally impacted by their diagnosis (Center for Disease Control and Prevention [CDC], 2014). The high cost of the care required, however,
leaves its mark on every individual involved: care can be time consuming and exorbitantly expensive, often involving insurance red tape and pricey legal battles. For many families, $60,000 per year for behavioral therapy is too high a price – these families are often required to watch their children suffer in silence.

Autism and poverty are therefore connected in almost every way; not only is autism care expensive, but it is often inaccessible to those who are uneducated, of a minority (be it racial, cultural, ethnic, etc.) or who live in a nonmetropolitan area – those who are, statistically, more likely to suffer from the hardships of poverty (Lavelle, Weinstein & Newhouse, 2014). If an individual is not educated in healthcare law, how will he or she know to fight for insurance coverage of costly therapies? If someone lives far from urban resources, how will he or she be able to reach out on behalf of a child?

Families who are otherwise struggling are often overwhelmed with an ASD diagnosis and remain unaided by a system only navigable by the rich or connected.

In this paper, I will discuss the details of autism spectrum disorder and its treatments, as well as their interactions with poverty, including an analysis of the institutional and individual impediments to care. This discussion will conclude with potential future work to alleviate the issue: including children with ASD in policies, practices, and family-level interventions that break down healthcare barriers.
ASD is a mysterious disorder: difficult to diagnose, and even more difficult to treat. Here, I will discuss the specifics of autism: the characteristics of the disorder, its diagnosis, and potential treatment options.

**SYMPTOMS.** People with ASD can have problems relating socially or emotionally to others – they may have trouble communicating, repeat certain behaviors, or be resistant to change. For example, children with autism may not meet particular developmental milestones: they be unresponsive to their name in conversation, may not understand the ebb and flow of exchanging ideas (i.e. regularly speak out of turn), or be able to evaluate the complexities of speech including vocal tone, volume, facial expression, and words to understand what is being said. Many people with ASD have unique ways of learning, paying attention, or reacting to sensory stimuli (e.g. loud sounds or bright colors). Symptoms of ASD can begin as early as infancy and often last a lifetime. ASD occurs in all racial, ethnic, and socioeconomic groups: the CDC estimates that about 1 in 68 children have been identified with an autism spectrum disorder (CDC, 2014).

**DIAGNOSIS.** That being said, today, more people than ever are being diagnosed with ASD. It is unclear how much of this increase is due to a natural increase in the incidence of ASD, changing cultural and social opinions regarding the disorder, or a change in the scientific definition of “autism.” Most likely, the increase is due to a combination of change social opinions and scientific definitions. As autism diagnoses become more prevalent due to better detection services and a more appropriate
medical definition for the spectrum of disorders, cultural attitudes are allowed to shift to a more educated, positive understanding of ASD.

There are certain risk factors for ASD: genetic predisposition, siblings with the disorder, prescription drugs taken during pregnancy, and parental age can all factor into the likelihood of an autism diagnosis (CDC, 2014). However, diagnosing ASD can be difficult, because there is no one medical test with conclusive results that point to ASD. Instead, a doctor may examine a child’s behavior and development to make a diagnosis (CDC, 2014). Research has shown that a diagnosis of autism at age two by an experienced professional can be reliable, but most children are not identified with ASD until after age four. Parents, however, often recognize symptoms of ASD before a child’s first birthday. Early diagnosis and treatment are essential to progress in ameliorating – or even alleviating - the symptoms of ASD (Handleman & Harris, 2000; National Research Council, 2001).

**TREATMENT.** Significant amounts of care can be necessary for children with ASD, and this comes in many shapes and forms: early intervention services, behavior and communication approaches, dietary approaches, medication, and alternative treatments can all factor into a treatment plan (CDC, 2014). It is important to note that the word “treatment” is utilized with caution. There are several schools of thought regarding therapy for ASD, including those who believe that ASD is not meant to be “treated” or “cured” – rather, it is something to be celebrated as special or unique about an individual. That being said, the large majority of the population chooses to
proceed with some form of therapy, either in the hopes of ameliorating symptoms – or alleviating them entirely.

Research shows that early intervention treatment services can improve a child’s development dramatically. From birth to three years old, such services can aid in the important skills of walking, talking, and interacting with others (National Dissemination Center for Children with Disabilities, 2013). But while early intervention is important, intervention at any age can be useful. Most prominent are behavior and communication approaches, including applied behavior analysis (ABA), “floortime,” and TEACCH.

Applied behavior analysis is, currently, the most recognized form of ASD treatment: having become widely accepted among healthcare professionals and used in many schools and treatment centers, ABA encourages positive behaviors and discourages negative behaviors to improve social, emotional, and communication skills (Autism Speaks, 2014; CDC, 2014). It is often publicized as the most effective form of treatment, but it is also the most expensive. “Floortime” focuses on emotional and relational development, as well as reactions to various sensory stimuli, while TEACCH uses visual cues to teach skills (CDC, 2014; UNC School of Medicine, 2014).

To provide a simplified example of how these therapies are implemented on a day-to-day basis, it is helpful to imagine a conversation between two people, one with ASD and one without: an ABA therapist might be present during this conversation and encourage their client to analyze different aspects of communication, including vocal tone, volume, facial expression, and wording. A therapist might discuss the connection between feelings of anger or excitement in conjunction with a loud voice, or the
association between hurtful words and expressions that indicate sadness. In addition, “practicing” communication skills is accompanied by sensory exposure therapy to develop an appropriate understanding of kind or unkind touch (e.g. painful or soft pressure when holding hands), or to develop comfort around uncomfortable stimuli (flashing lights, unexpected loud noises, etc.). A therapist works to provide positive examples of interaction with the world around us so that an individual with ASD may grow to develop positive personal relationships with the people and environments in their lives.

Each form of therapy, including occupational, sensory integration, speech, and the more specific behavioral therapies above, can be employed in tandem with dietary approaches (i.e. special diets that eliminate certain foods while including vitamins and supplements) as well as medications. Medications, in particular, can work to alleviate the most severe or dangerous symptoms of some ASD diagnoses, including tantrums, aggression, or self-injury (CDC, 2014). These drugs are typically expensive antipsychotics that may or may not be effective. Most importantly, ASD care of any type to manage ASD symptoms can be vital, lest a child fall further behind academically, socially, or emotionally.

Institutional Impediments to Care
In an attempt to better understand the intersection between the financial hardships of poverty and caring for a child with ASD, I will discuss the specifics of the high cost of care and insurance coverage.

**HIGH COST OF CARE.** Treatment options bring us to the crux of the issue: autism can be emotionally crippling to both the individuals diagnosed and the families who love them, but beyond these sentiments, there are extreme expenses. For any family, but especially those families who are severely financially or socially disadvantaged, these expenses can be overwhelming. Cost of care is the first serious issue to be discussed regarding ASD and its relationship with poverty. Expenses can include healthcare costs, education, therapy specific to ASD, family-based services and caregiver time. It is estimated that the amount required to care for a child with ASD is at least $17,000 more per year than to care for a child without ASD. For more severe ASD, costs per year increase to over $21,000 (Lavelle, Weinstein & Newhouse, 2014). On average, medical expenditures for children with ASD were 4.1 – 6.2 times greater than for those without ASD; this translates to $4,110 - $6,200 per year (Shimabukuro, Gross & Rice, 2007). In addition to the basic medical costs as listed above, autism therapies – largely considered necessary today - are overwhelmingly expensive. Disadvantaged families simply do not have the financial resources to give their children the therapies most likely to improve their quality of life.

**LOW INSURANCE COVERAGE.** Previous analyses have shown increased health care expenses for children with ASD but have not yet provided comprehensive
documentation of the total economic burden on needy families. Currently, insurance plays a large role in covering some – but not all – of these costs. Mental health (including developmental disorders like ASD) and physical ailments are required to be covered equally under insurance: this is referred to as “parity” in healthcare (Gilligan, 2013). Under the Affordable Care Act, coverage for behavioral therapies is required as a part of mental health parity. Individual states, however, are able to decide specifically what therapies are considered “mental health parity.” Some states have decided to include applied behavior analysis (ABA), which is now considered a “standard” of care, while other states have excluded it from their list of covered therapies (Gilligan, 2013).

Again, ABA is a form of behavior analysis that uses rewards to encourage positive behaviors and discourage negative ones. It is an intensive form of therapy, often performed many times a week – even every day – in a one-on-one setting. ABA generally runs between $40,000 - $60,000 per child per year (Amendah, Grosse, Peacock & Mandell, 2011). Many of its advocates say that ABA is worth the cost because it works: some studies have shown that even 40% of children who receive behavior analysis therapy do not require special education by the age of six (Zarembo, 2011). While it has not yet been subjected to a randomized trial to prove its effectiveness, prestigious professionals, including the Office of the Surgeon General and the American Academy of Pediatrics, have endorsed it as a successful treatment (Gilligan, 2013).

California provides a unique example of this coverage query in that it has mandated that all private insurance policies cover evidence-based autism treatment, including ABA, but exempts Medi-Cal (i.e. California’s Medicaid welfare program) from
that requirement. As a result, families with private insurance have ABA coverage for their children, while low-income or publicly insured families do not (Zarembo, 2011). This gap represents the institutional policy imbalance that many families affected by ASD experience across the country. If ABA serves as the standard for successful autism treatment, why must so many families go without it? It is a very rare case when the family of a child with ASD can afford to pay for ABA out-of-pocket, and statistically far more unlikely for families to be unable to pay anything at all. The legislation that mandated coverage for behavioral therapies recognized the need for therapy as urgent while excluding the population for whom that urgency is the most pressing: how can needs be urgent for those with money, and not urgent for those without? Insurance companies have routinely denied coverage for ASD therapies, and it is often the most sensitive families who suffer.

**Individual Impediments to Care**

Not only are political and institutional hardships to be considered, but individual hardships as well: disadvantaged families may not be able to receive the care they need due to societal discrimination, even before cost is considered. Access to care is obviously limited for families of low socioeconomic status, but access to care is also limited for racial and ethnic minorities, families with low parental education, and families living in nonmetropolitan areas (Thomas, Ellis, & McLaurin, 2007). Underserved families may not be able to advocate for services, afford or travel to services, or may
even be denied due to discrimination against their heritage. Here, I will discuss several versions of this individual discrimination and the resulting impact on access to ASD care.

**RACIAL, ETHNIC, CULTURAL DISCRIMINATION.** It can be difficult for an underserved family to get or understand a diagnosis – for many, autism is now a buzzword that links to services, and that diagnosis is precious. For example, children with ASD of a minority (racial or ethnic) have been found to receive services at a later age than white children, as well as a different mix of services than their white counterparts. Racial and ethnic minority families had half the odds of using a case manager, and just a quarter of the odds of using a developmental pediatrician or psychologist (Levy et al., 2003; Mandell, Listerus, Levy & Pinto-Martin, 2002). For instance, the California state Department of Developmental Services spent an average of $11,723 per year per white child with ASD, compared to $11,063 per Asian child, $7,634 per Latino child, and $6,593 per black child (Zarembo, 2011). Data from the public school system indicates that whites are far more likely to receive even basic services such as occupational therapy to assist with motor skills (Thomas, Ellis, McLaurin et al., 2007).

**PARENTAL EDUCATION AS AN IMPEDIMENT TO SERVICES.** Additionally, low parental education makes it difficult for families to advocate on behalf of their children. Unfamiliarity with the system or a low sense of academic self-efficacy can be attributed to poverty and its effects, and these effects shine through in the connection between parental understanding of services and the actual implementation of those services (Thomas, Ellis & McLaurin, 2007). A parent without a high school diploma may have
been taught a life-long lesson of educational hardship, leading them to be unfamiliar with the public school system and the rights of an individual student to proper therapy and care. Parents with a college or graduate degree had two to four times the odds of seeking out a neurologist for their child with ASD. A parent without a diploma may not understand that they are capable of fighting successfully for coverage they might have otherwise been denied (Thomas, Ellis & McLaurin, 2007). In a system that happens to support the wealthy and leaves everyone else to fend for themselves, undereducated parents and their ASD children are often left behind.

**GEOGRAPHICAL LIMITATIONS TO ACCESS.** Location can pose an issue with regards to accessing services, as well. Nonmetropolitan families struggle with the sheer geographical limitations of resources; much like rural poverty (and, in fact, the two go hand in hand), limited access to services poses an insurmountable issue for families in a rural area. None but the most bustling of cities can be considered “packed” with ASD resources, and these may be hours or days of travel away from the family that works their own plot of land – not to mention, rural schools may be unable to provide the required resources (Thomas, Ellis & McLaurin, 2007). Further, it may be hard even to find a diagnosis of autism: it is surprising how much diagnosis rates – and therefore spending on treatment – vary from place to place. In the state of California, 1.1% of all public elementary school students were found to have an ASD, but the autism rate in Orange County (an affluent, metropolitan area) is almost triple that of Fresno County (a more remotely located, less prosperous area) (Zarembo, 2011). Often, rural districts will report no autistic students at all, for lack of understanding, lack of resources, or both.
Interconnectedness and the Domino Effect

What is so incredible about this network of institutional and individual barriers to care is the sense of interconnectivity: an individual rarely experiences one issue at a time, but rather, one issue can lead to another, which leads to another and so on and so forth. Many individuals – communities, even – are forced to assume the mantle of historic subjugation under which our people have operated for hundreds of years: people who are different are lesser, and those who are lesser are thereby less deserving. If an individual is black, it is statistically likely to mean that he or she is undereducated. A lack of education breeds poverty, and poverty finds itself in pockets of low-income communities interspersed with pockets of affluence – though the two never mix. A low-income community likely lacks the resources (financial or otherwise) to combat a lack of insurance: not only can residents not afford privatized insurance to pay for therapies, but their communities are unable to compensate by holding parenting classes, improving teaching skills in schools, or bringing highly-trained physicians.

Barriers to care build on layers of varying types of inequality, and it is vital that we work to better understand how to combat these barriers with further research on their mechanisms.

**SOCIOECONOMIC DIFFERENCES IN CARE.** It is not difficult to understand the blatant mechanism behind socioeconomic differences in care for ASD: as some families are able to afford treatment, their children can thrive, while those who cannot afford treatment are forced to suffer in silence. Insurance companies continue to support the socioeconomic divide with coverage plans built only for families who can afford them.
Potential outcomes of socioeconomic differences in care include a continuation of the cycle of poverty (as families may spend more and more to access treatment, continuing the cycle of debt), or a larger socioeconomic divide in the special-needs community (as affluent families work to alleviate symptoms with treatment while impoverished families must live with the struggle). A variation in socioeconomic access to treatment could eventually lead to a world where only low-socioeconomic status individuals live with ASD. To prevent this terrible, inequitable outcome, it is important to ask families in need specific questions regarding how to better their support system, how to aid them financially, or how to suit ASD care to their time, schedule, or personal lifestyles so that their children can flourish.

**Racial, Cultural, and Ethnic Differences in Care.** Racial differences in access to care may be more difficult to understand, but the outcomes of these differences are clear: white families receive better treatment, potentially furthering the racial divide in our country and allowing it to continue as the next generation of special-needs children are separated by color. Research describes significantly lower odds of service use among racial and ethnic minorities: this is a result of many issues coalescing – it can involve economic factors, service sector factors, as well as cultural factors. We must ask: is active discrimination present? Is there a lack of cultural resources built specifically to support diverse populations with ASD? How is our society holding back families of diverse backgrounds while supporting white families? Not to mention, institutionalized discrimination leading to a general mistrust of the system and social stigma against both racial differences and ASD are likely to be significant (Schnittker,
2003; Edwards, 2003). Future work will involve clarifying racial and ethnic minority families’ perceptions of, attitudes toward and experiences within the system of care for ASD, to better understand barriers to service provision. Families of diverse backgrounds must be represented in treatment research, and thereby included in the policies that regulate the treatment that follows. Are ASD treatment communities must be inclusive of unique cultural heritages: asking diverse families directly via survey how to improve treatment communities is key. Regardless of their origins, racial differences are striking in the ASD system of care, and must be ameliorated immediately.

**PARENTAL EDUCATION DIFFERENCES IN CARE.** The connection between parental education levels and access to care is clear: the more educated the parent, the more likely the family is to receive care, as an educated parent understands a child’s rights to care, how to actively engage the community in seeking that care, and has the personal resources to never back down from the fight. Outcomes of parental education backgrounds, again, include a continuation of the cycle: an educated parent can get an ASD child into a classroom with a personal aide, helping that child through school and possibly onto a college degree. Parents with low educational attainment may not be as successful in this endeavor, and their child may fall behind both academically and socially. In order to better research this effect, it is necessary to study the way ASD services are marketed: are they clear and in layman’s terms, are they easily accessible for families from all walks of life? Resources for ASD (e.g. community support, classroom assistance, therapies, etc.) shouldn’t be intimidating to access: they should be in multiple languages, in understandable, non-medical phrasing, and easily accessed in
different socioeconomic communities. Enabling more educational equality in access to care leads to better outcomes for all.

**GEOGRAPHICAL DIFFERENCES IN CARE.** Geographical location simply limits access to care resources: ASD treatment centers, support groups, and medical specialists are all more likely to be located in a more populated area. Outcomes from these geographical limitations are simple, but striking: children with ASD in rural areas, being unsupported in the classroom and community, may miss out on opportunities to grow socially or emotionally, leading to more prominent differences between urban and rural poverty, educational achievement, etc. In an attempt to alleviate this issue, it is important to study rural families and tailor resources to suit their needs: ASD centers must be built for small communities. It is a requirement that we include nonmetropolitan residents in surveys and data collection, allowing rural families to be heard and accounted for. Future work is needed to assess the variation in services between urban and rural areas, examine the cultural differences between the two, and determine the effects of ASD service shortages and build policies to alleviate them. Studying the population in question will allow unpacking of the issue of geographic location limitation of services.

**Why Change is Vital**

Unfortunately, even with recent healthcare reforms, it does not appear that change is on the horizon: our healthcare system remains a largely economic machine, a symptom of American capitalism and consumer culture, rather than an entity that works
to keep our people well. Countless individuals – including these children with ASD and their families – are forced to participate, unwittingly or unwillingly, in a system that not only refuses to help them, but also actively hurts them via that refusal.

It is important that we remember our rights, as well as the rights of others. There is a certain baseline of functioning that we, as sentient beings who feel pain and fear, are entitled to simply for existing. This baseline allows every individual to interact healthily and happily with the world around him or her, and to pursue his or her dreams – it ensures that all people are treated well and as equally as possible, with respect to their dignity and individual story and experience.

Nussbaum explains it well, with her theories on capabilities: our society can only be considered good if the individuals within it are secured real opportunities (Nussbaum, 2011). Opportunities might pertain bodily health and integrity, but also personal senses, imagination, and thought, as well as emotions, practical reason, and play (Nussbaum, 2003). Citizens must be afforded the opportunity to be well physically and emotionally. An individual who is forced to remain a victim of their circumstances when his or her capabilities are being violated (e.g. an individual with ASD being unable to access therapy to improve communication skills in order to preserve bodily and emotional health) is uncared for by our society (Alkire, 2009).

The idea of capability clarifies an idea that our government (or its companies and lobbyists), unfortunately, does not hold dear: healthcare is a right, not a privilege. It seems we operate under a system in which capabilities – opportunities to be healthy and achieve one’s dreams – are currently commodities to be bought and sold.
Moving Forward: Ideas to Consider in Policy Reform

So how do we proceed? In what way can we move forward to care respectfully for every family struggling with ASD? I will now briefly discuss potential remedies and policy implications to alleviate low-access-to-care.

First, it is important to address the fact that populations in this paper are likely to be missing families with the least disposable resources, families who might be unsure if their child has ASD, who were so disconnected from a system of providers that they could not be reached – or whose child with ASD was so severely needy that they were incapable of devoting the time or energy to participate in research. A lack of access to services is likely underreported, as those who are in the most grave need are often the most difficult to reach. As well as gaining the specific data for families listed above (i.e. varying socioeconomic levels, ethnic backgrounds, etc.), the entirety of ASD culture would benefit from future work that identifies the skills families need to advocate for and successfully navigate through the system of care that all children with ASD deserve.

In addition, it would be valuable to study and better articulate the types of support that families living with ASD need to be successful in maintaining their own emotional health in devoting their energy to their child.

Once further data regarding need is acquired, we must then move forward to meet that need: as stated previously, a violation of capability is a wrong committed by our society. It is a moral requirement that our human community move forward with everyone in mind, not only a select few. Community resource centers must be provided, teachers must be trained to be more inclusive, and physicians must be skilled in
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Diagnosis and potential treatment of ASD. Not only this, but also the advancement of all populations to a level of equality previously unseen: our culture must move forward believing that every individual among us deserves to be given the opportunity to succeed, creating a much needed feeling of inclusivity and care.

Last, there is a vital need for policy reform: privatized insurance, while fitting in with the American capitalist ideal, does not aid many in achieving their highest degree of capability – a select few are able to utilize the system to their advantage, while others are left to struggle unassisted (or with subpar assistance). Moving toward a single-payer insurance system is our next step in improving our healthcare policy, as it will work close the divide between rich and poor regarding health capability. In the distant future, however, it will be important to consider our understanding of insurance and healthcare entirely: our entire medical system is structured around finance as opposed to patient care. Students must take out huge loans to enter medical school, likely influencing them to train for a more highly-paid subspecialty in which 30 minute surgeries earn them thousands of dollars more than 30 minute patient conversations. With insurance and pharmaceutical companies in the lobbying picture, no one is there to regulate prices beyond CEOs who line their pockets. A reconsideration of monetary participation in healthcare is more critical than ever.

While it is true that there are many barriers to care, be they cultural, economic, or geographical, there are also many ways to overcome these barriers, and many more reasons why moving forward to better care is important; future work to increase the standard of care for all ASD families is vital.
Conclusions

In conclusion, autism spectrum disorders affect many families today, and these families often need support. ASD can be a life-changing diagnosis for children, teens, and adults alike, as well as for the families who love and care for these individuals. Some diagnoses mean a child will never walk, talk, or toilet themselves, while others mean that there may simply be something “different” about the way these individuals relate to others, learn, or understand the world. Diagnosis is very subjective, and it can be difficult to pinpoint risk factors, but ASD rates are on the rise due to shifting cultural norms: autism is becoming more important to us.

That being said, many families struggle with an ASD diagnosis, and finances are often a factor. Research has shown that there is a significant difference in treatment for families in poverty compared to affluent families. ASD therapies are exorbitantly expensive, and families in poverty just don’t have the funds – or the insurance coverage – to provide them for their children. Specifically, states have the ability to decide whether or not certain therapies (including the most successful form, applied behavior analysis therapy) will be covered by insurance: private insurers may cover it, while those families who need the public insurance coverage must go without. It then becomes an issue of, “Who deserves treatment and progress? People with money or people without?”

Not only this, but access to services is an issue for families in poverty. Research shows that if parents didn’t receive a college or graduate degree, they are far less likely to be able to successfully advocate for ASD services for their child. Racial and ethnic
minority families are often in the same boat, due to differences in cultural norms, as well as institutionalized discrimination. If a family does not live in an area where resources are common, they are far less likely to receive successful ASD services. Are all children not equally deserving of care? In fact, are children in poverty not more deserving of public services they are unable to receive privately? Is there a reason for the separation of public and private services?

These are complicated questions, and policy reform should attempt to address them: research findings underscore the importance of including children with ASD in efforts to develop policy, practice, and family-level interventions that address barriers to care. It is our commitment to one another as a society to provide everyone with the capability to succeed.
References


