



Regulatory, Policy, and Practice Review

Background

A variety of state statutory provisions, regulations, policies, and/or practices have been identified as playing key roles in limiting access to child care for children with disabilities and other special needs. Additionally, local policies and practices have been identified that are allowed to vary in accordance with state law. While not every potential impediment to access to inclusive child care is presented here, the information highlights those issues recognized as having been barriers or as having exceptional potential for becoming barriers.⁶⁹

To identify these impediments to inclusion, researchers conducted a legal review and analysis of existing relevant statutes, regulations, and policy interpretations; telephone interviews with key informants; and a review of the telephone surveys of child care providers and the focus group discussions conducted by this project.

One source of confusion about legal rights and responsibilities is the variety of overlapping, inconsistent definitions regarding who is covered under which laws. Moreover, since some of these laws are civil rights laws and some are entitlement laws, the remedies available to individuals with disabilities under particular laws also differ. The laws addressing the needs and rights of individuals with disabilities will never cease providing somewhat differing coverage, nor should they, since different subgroups of those with disabilities may need different accommodations. However, it is important to be mindful of these inconsistencies and to minimize them wherever possible, especially when writing new laws and/or regulations.

The differences in the ways that legislation defines and addresses disability also have repercussions on access to services, especially when parents and child care providers generally do not consider children in their care to have “special needs” or disabilities. For this reason, it is critically important that information, surveys, and other tools be created and shared to help parents and service providers better understand how to both identify and meet the needs of children with disabilities. If this training and support is not provided, many children whose families and child care providers are not equipped to identify their needs may lose the benefit of access to services and protection to which they are entitled.⁷⁰

Legal Rights and Responsibilities

Lack of Information

Review of materials generated by this project consistently turned up a law-related problem expressed both explicitly and implicitly. Interestingly, perhaps the greatest legal problem was not a particular statutory section or regulation that resulted in a major barrier to inclusion, but rather that each group — whether parents, teachers/providers, specialists, support agencies, or school personnel — had insufficient knowledge and understanding of existing laws. As a consequence, laws that would actually assist families in gaining access to child care were unknown or misunderstood.

The telephone survey revealed that only 20% of respondents from child care centers (CCCs) and 6% of family child care homes (FCCs) had received training in their rights and responsibilities under the Americans with Disabilities Act (ADA). Repeatedly in the focus group discussions, it was apparent that numerous parents and providers in particular lacked an understanding of their respective rights and responsibilities. It is only when parents and providers are provided with such knowledge that they can use this information to request and obtain the care and services to which they are entitled or have the possibility of accessing. Thus, a key barrier to inclusive child care identified in this effort was a lack of information about legal rights and responsibilities under relevant laws.

However, the problem identified went deeper than a general lack of information; it included a constellation of additional problems, including lack of:

- Live or taped training for child care providers, licensing personnel, and other related personnel and specialists (e.g., school districts, resource and referral staff, regional center staff, etc.) in legal rights and responsibilities under relevant laws (e.g., ADA, Individuals with Disabilities Education Act [IDEA], Unruh Civil Rights Law, etc.).
- Official written information for parents at appropriate literacy levels and in appropriate languages concerning legal rights and responsibilities.
- Information for parents and others in other than handout or brochure form and in appropriate languages concerning legal rights and responsibilities (e.g., public service announcements, videos, radio spots, billboards, transit posters, table displays, etc.).
- Availability of information on a continuing basis, given at appropriate times and in accessible locations (i.e., parents are often given information when they are already overwhelmed with the needs of their child with a disability or

other special need, or information is given at one stage, but conditions change and parents are not given new information).

- Recognition that individuals enter the child care and specialized service systems from a variety of points (e.g., birth hospital, child care, pediatrician, self-referral, school), and each point should be able to direct them to the other parts of the system they need.

Increasing the knowledge base of all those involved with the system, specifically regarding their legal rights and responsibilities under the law, would minimize the occurrence of adversarial confrontations. Perhaps more importantly, this would help ensure that those individuals who never learn their rights or are fearful of exercising them would not receive less than those who are knowledgeable and feel comfortable speaking up.

Lack of Skill to Adequately Enforce the Law

For families, just knowing their legal rights does not ensure access to services. Information is a necessary, but not sufficient, means of enforcing rights. Enforcement requires that rights be exercised, and all too often individuals may have information, but lack the skills and knowledge about processes for enforcement to make legal rights a reality. Skill building for advocacy must include:

- An understanding of available advocacy resources (as applies to inclusive child care).
- Knowledge about processes (i.e., such as moving up a chain of command when one is unhappy with a decision at a lower level).
- Confidence-building exercises so that individuals are not intimidated by authority figures.
- Alterations in certain ways of thinking (i.e., turning feelings of guilt for questioning a decision or exercising due process rights into feelings of strength and self-regard).

It is the combination of information on legal rights for children with disabilities and special needs and skill building for advocacy so families may competently represent those legal rights when necessary, that will most likely ensure children and families are receiving the services to which they are entitled.

Department of Social Services, Community Care Licensing

Including children with disabilities and other special needs in child care requires that there be no significant impediment created by the child care licensing laws themselves.⁷¹ The following section reviews the primary licensing impediments.

Children With Special Health Care Needs

A significant barrier to serving children in regulated child care settings is the current inability of providers to perform certain incidental medical procedures. The California Health and Safety Code section states that a child day care facility “provides non-medical care to children under 18 years of age in need of personal services, supervision or assistance essential for sustaining activities of daily living or for the protection of the individual on less than a 24-hour basis.” No statutory definition of “non-medical” exists. California is relatively unique in having this non-medical language in its licensing statute.⁷²

The passage of the ADA in 1990 established that state licensing provisions could not screen out individuals with disabilities, unless states can show that such requirements are necessary for the provision of the service, program, or activity. A public entity may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities, but these requirements must be based on real risks.

The ADA necessitated a fresh look at existing statutes and regulations, and it appears that licensing restrictions against the provision of certain procedures are too restrictive to be in compliance with the ADA. This review has been complicated because it has necessitated not only a look at licensing statutes, but also review of statutes and regulations governing the health and allied health professions. Like other states, California has a Medical Practice Act (Cal. Bus. & Prof. Code Section 200 et seq.), Nursing Practice Act (Cal. Bus. & Prof. Code Section 2700 et seq.), and other related laws governing the responsibilities of various health and allied health professionals. These laws describe the scope of practice for each profession and also detail to whom and under what circumstances various aspects of these practices may be delegated.

During the past several years, through administrative advocacy, legislation, and the filing of lawsuits, a number of health procedures previously forbidden by Community Care Licensing (CCL) have now been allowed, typically under certain conditions.⁷³ These procedures include the use of an Epi-Pen (a pre-measured injection device used by lay people when an individual has a life-threatening allergic reaction), blood glucose monitoring for individuals with diabetes, administration of inhaled medication through nebulizers, and gastrostomy tube feedings.

CCL has been concerned about its authority to define which procedures are appropriate under the current statute. Various organizations concerned with the availability of care for children with special needs and cognizant of ADA requirements have continued

to urge the Department of Social Services (DSS) for additional rulings on other procedures and have also drafted possible legislation to address this issue. Changes in technology will mean that this issue will require continuing attention, even if legislation is passed. New procedures will likely be developed that lay people with proper training and supervision may perform, and certain procedures once thought to be strictly under the jurisdiction of licensed professionals will likely be performed by non-professionals.

Another related licensing barrier concerning health care is that currently, when licensed health professionals (e.g., registered nurses) are also community care licensees (e.g., family child care providers), they may not exercise their health skills (e.g., giving an injection of insulin to a child with diabetes) because doing so would violate the community care facility statute, which speaks to non-medical care. In effect, this has stymied development of sensible hybrid facilities that would go far to meet the needs of children with special health care concerns. There are certainly nurses in the community who are licensed family child care providers or center-based staff, and could perform valuable, needed services if this legal impediment was eliminated. Doing so would enable a registered nurse, for example, to give a needed insulin injection to a child with diabetes in a child care setting.

The following code sections found in Title 22, Health and Safety Code have been identified as barriers to child care for children with disabilities or special needs and impede compliance with the ADA and Unruh Civil Rights Act.

1. Non-Ambulatory Status (Sections 101161, 101174, 102371)

Licensed child care facilities require providers to obtain non-ambulatory fire clearances to enable children with physical and developmental disabilities to participate in the program. The law defines those children who need a non-ambulatory clearance as those with certain physical limitations as well as those who are unable to follow instructions in an emergency (see Health and Safety Code Section 13131). Issues have arisen primarily in the implementation of these rules. Problems include:

- Lack of standardized information and/or training to determine exactly who requires non-ambulatory clearances (for both child care providers and licensing evaluators).
- Delays in obtaining clearances, making it difficult for facilities to accept children.
- Lack of information about exactly what is required to obtain a non-ambulatory fire clearance.
- The response of licensing to finding a child who would trigger non-ambulatory status in a center without that clearance.

2. Use of the term “age appropriate”

Use of the term “age appropriate” has caused problems for licensed child care providers in situations where licensing has required permission for children with developmental delays to remain either in infant care or toddler care beyond the age where licensing would normally allow the child to stay in that setting (e.g., toddler option or infant care license).

3. Administration of medication to children with disabilities

Current licensing laws and regulations do not require, but permit, the administration of medication. Because the administration of medication may be considered a reasonable accommodation, facilities no longer have the option of refusing to administer medication if the need for it is the result of a child’s disability. Consequently, the current permissive language may confuse providers about their legal obligations.

4. Admissions policies and requirement of meeting individual needs (Section 101218)

Current licensing regulations require providers to demonstrate their ability to meet individual children’s needs, including situations where they serve children with disabilities and other special needs. As presently drafted, these regulations give discretion to evaluators to support the denial of care to children with disabilities and other special needs, rather than promoting the inclusion of these children through other measures (e.g., collaborating with other agencies).

5. Infant needs and services plan

Current regulations require that infant services plans should include any services needed by the infant that are different from those provided by the center’s standard program (e.g., “special exercises for infants with physical disabilities.”).⁷⁴

If an infant has any identified disability, child care programs should make every effort to coordinate with early intervention or other programs. Sharing plans and recommendations among relevant staff would contribute to meeting the child’s individual needs.

Other Licensing Barriers

Analysis of focus group transcripts by a legal policy expert found repeated incidences of policy or regulatory interpretation that was cited in 15 of the 18 focus groups. Parents and child care providers reported that several provisions within the licensing statutes (e.g., restrictions on child capacity and adequacy of supervision) are differentially applied, so that citations for violation of these provisions

are more likely to be applied to programs serving children with special needs.

Analysis of focus group transcripts by a legal policy expert found repeated incidences of policy or regulatory interpretation that was cited in 15 of the 18 focus groups. Parents and child care providers reported that several provisions within the licensing statutes (e.g., restrictions on child capacity and adequacy of supervision) are differentially applied, so that citations for violation of these provisions are more likely to be applied to programs serving children with special needs.

Failure to Provide Accurate Legal Information

A second area of concern to licensed child care providers is the role of the licensing evaluator in providing legal advice to child care programs. The evaluator should be a source of referral to organizations that can provide legal information about the ADA and California's Unruh Civil Rights Law and should not be in the position of giving out potentially incorrect information. Examples were given by a number of child care providers and administrators who reported that both at licensing orientations and during site visits, licensing personnel indicated that children with disabilities need not be served in child care facilities and that care of some children should be terminated because of their behavior or disability.

Affirmative Efforts Toward Inclusion and Accessibility

The law can be an affirmative force as well as a barrier. In addition to eliminating provisions that serve as barriers, it would also be possible to consider more affirmative legislation. Alternatively, CCL could provide guidance material for licensees as an appendix to its regulations, as is done by many other states. Topics for affirmative provisions or guidance could include appropriate accessibility for indoor and outdoor space, collaboration between early intervention and special education services, and confidentiality and consent issues.

Lanterman Developmental Disabilities Services Act

Current law places a strong emphasis on providing opportunities for children with developmental disabilities to live with their families.⁷⁵ "The department [DDS] and regional centers shall give a very high priority to the development and expansion of services and supports designated to assist families that are caring for their children at home. ... This assistance may include, but is not limited to ... day care, ... [and] child care. ..." ⁷⁶ According to the statute, the regional center may pay only the cost of the day care service that exceeds the cost

of providing day care services to a child without disabilities, but can pay in excess of that amount when a family can demonstrate financial need and when doing so will enable the child to remain in the family home.

As part of this legal review, 15 of 21 Regional Center Purchase of Service Policies for Child Care were examined. While all provide for the purchase of child care, they differ significantly on a variety of dimensions. These dimensions include the:

- (1) Number of hours of child care they will make available.
- (2) Employment status of the parent (some require work only, while others allow care when a parent is in training or school.
- (3) Number of hours parents must be working or in school to be eligible.
- (4) Nature of the needs of the child.
- (5) Time when care is available (one policy only allows the purchase of care between the hours of 7 a.m. and 6 p.m.).
- (6) Age of the child when care will be paid for in its entirety.
- (7) Share of cost paid for by the families.

Despite the necessity of individualized assessments and the possibility of exceptions from the policy, these standardized policies are not necessarily supportive of families remaining together, which forms their statutory basis. Additionally, it appears from some of the interviews and focus groups that parents are not always informed of the availability of this possible service, nor that there could be exceptions to the standard policy.

Individuals with Disabilities Education Act: Early Start and Special Education

Lack of Understanding of the Law/Eligibility for Services

Insufficient numbers of child care programs understand the early intervention and special education systems, including how to access services for children they identify. Regional centers and local education agencies (LEAs) are responsible for Child Find activities. One of the primary referral sources listed in the statute is child care. Regional centers and LEAs have a mandatory duty to inform primary referral sources of the eligibility criteria for early intervention services, types of early intervention services available through Early Start, contact persons and telephone numbers for regional centers and LEAs, and the federal requirement that a referral shall be made to the regional center or LEA within two working days of identification of an infant or toddler who is in need of early intervention services.

It appears from interviews with stakeholders that the degree to which this is happening varies significantly from county to county, depending on whether there are established relationships between systems. Generally speaking, few publicity campaigns have been targeted towards child care, although there have been some positive efforts. For example, in San Bernardino County, Early Start personnel have been invited to participate in licensing orientations.

Lack of Awareness About IFSPs and IEPs

Insufficient numbers of parents and providers are aware that child care can be a service listed on an Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP). Current law provides that services on an IFSP are to be designated either as a required service or a non-required service. Child care is listed as one of the possible non-required services.

Insufficient numbers of parents and providers are aware that child care can be a non-required service listed on an IFSP or that special education services provided in child care settings can be called for within the IEP. Typically, the family is responsible for paying for the child care service.

Lack of Understanding About Natural Environments

There is a lack of information and understanding about the provisions concerning “natural environments” for infants and toddlers with or at risk for disabilities and “least restrictive environments” for preschool children. The 1997 Amendments to the Individuals with Disabilities Education Act (IDEA) contained a new provision for IFSPs. Federal law now states that the IFSP must include a “statement of natural environments in which early intervention services shall appropriately be provided, including a justification of the extent, if any, to which the services will not be provided in a natural environment” (20 U.S.C. Ch. 33 1436 Section [d][7]). Its regulations define natural environments as “settings that are natural or normal for the child’s age peers who have no disabilities.”⁷⁷

California’s regulations further define these environments as “settings that are natural or typical for the infant or toddler’s age peers who have no disability including the home and community settings in which children without disabilities participate.” California Code of Regulations, Title 17 Section 52000[b][35]) goes on to further specify that the IFSP must describe the location where the early intervention services will be delivered, “such as home, child care, school program, or private program. ...”⁷⁸ In addition, in conformance with federal law, the statement must include a justification of the extent, if any, to which the services will not be provided in a natural environment. While these provisions do not require that child care be the setting of choice, it is certainly clear that if a child is already being served in child care and is identified as in need of an early intervention service, and the service can be provided in child care, then child care would be the appropriate setting for the service.

Similarly, federal law requires justification on a child's IEP if services are not provided in the "regular classroom." This creates a unique and challenging situation in California, as there is no universal preschool program or regular classroom for 3- and 4-year-old children. However, there is also no restriction against providing special education and related services in child care settings.

Establishment of Clear Policies in Child Care Settings

Increasing numbers of early intervention specialists, special educators, and other specialists provide services in licensed child care settings. A lack of clarity exists about various requirements and how they apply, in terms of screening, choice of these personnel, and supervision issues. It is essential that these issues are resolved if the systems are to work together. This concern was raised by key informants and participants in the focus groups.

Early Education Services for Preschoolers

California Education Code provides that "early education services for preschool children shall include interacting and consulting with ... regular preschool teachers ... as needed, to demonstrate developmentally appropriate activities necessary to implement the child's IEP."⁷⁹

As with so many aspects of the law, there is great variation in how effectively this mandate is carried out. At times, this requirement is implemented in some child care settings, but not others. In some communities, implementation only occurs for Head Start or school district programs, but not for private preschools. At other times, only generic training, rather than individualized interactions and consultations, is taking place.

Lack of Information on Transportation Availability

One of the current barriers to including children with disabilities in child care is the lack of transportation from the site where their early intervention/special education services may be provided and their child care setting. This is particularly difficult for families who may live in one city, have child care in another, and work in yet another. School district transportation policies are not required nor designed to consider the needs of working families.

Title 5: Child Development Programs

Multiple Definitions

The Education Code uses a variety of definitions for children with disabilities and other special needs, and these definitions are not consistent between the child care portions of the law and the early intervention/special education provisions. Additionally, the Child Development Division's use of the term "children with special needs" to include not only children with disabilities, but also children at risk of abuse and neglect and those who experience limited English proficiency tends to further confuse both parents and service providers. The law uses a number of terms, many of which are no longer considered appropriate in the field of special education, including "severely handicapped," "exceptional needs," and "special needs."

Issues Around Special Needs Reimbursement

California currently applies a rate adjustment for qualified children with disabilities through both its alternative payment programs (APP) and contracted programs. However, concerns have arisen about the scope of children covered, limitations on situations when such a rate adjustment is available, and the difficulties that arise when tying reimbursement to market rates. This latter point is significant because providers may not charge parents of children with disabilities additional fees for making accommodations even though their costs may be higher, so these higher costs are never reflected in market rates.

Methods for tracking who is claiming the higher rate are also lacking, making it difficult to tell how well utilized it is. However, key informants mentioned that adjustment rates are underutilized in both the APP and contracted programs because the way the system works, no additional funds are actually provided; instead, fewer children are served, or less units of service are provided. Additionally, individuals who fit within several categories, such as an infant with a disability, may not accumulate or aggregate adjustments; only one rate adjustment may be claimed.

Compliance with the Americans with Disabilities Act

This Education Code section requires contractors to comply with the ADA. Recent decisions of the U.S. Supreme Court have significantly cut back the scope of protections for individuals with disabilities under the ADA. However, California law has maintained and even enhanced protections through its Unruh Civil Rights Law.⁸⁰

Scope of Responsibilities of Resource & Referral Agencies

Current law provides that Resource and Referral Agencies (R&Rs) identify the full range of child care services available in a community. However, there is nothing that requires any enhanced services for families with children who have disabilities. A number of R&Rs have resources such as books, equipment, and toy lending libraries that could include accessible toys and adaptive equipment which could be used by children with various disabilities.⁸¹

The law also does not specify that the agencies track the number of requests for care for children with disabilities, data that could be of value in ensuring appropriate care services are available for all children.

California Work Opportunity and Responsibility to Kids (CalWORKs)

CalWORKs regulations provide for parents to have good cause for non-participation in welfare-to-work programs when there is “unavailability of suitable special needs child care for children with identified special needs including, but not limited to, disabilities or chronic illnesses.” Like many well-intentioned provisions of law, this one also has had some unintended, negative consequences. Many parents of children with disabilities and other special needs want to work, and the exemption is not desired.⁸²

Additionally, time limits still apply (42-713.4). Interviews revealed that some parents are urged and/or encouraged by welfare personnel to take the exemption (i.e., not maintain employment because of the lack of available child care). Parents too often are not given the option of trying to work and having child care paid for because the welfare departments find it easier to grant good cause for non-participation. At this point, it is difficult to assess the incidence of this problem because there does not appear to be any data on those claiming good cause for non-participation based upon having a child with a disability.

-
- 69 This document does not focus on legal impediments that are not particular to the care of children with special needs such as race discrimination or discrimination based upon primary language. Nonetheless, as evidenced by material elicited during the focus group sessions, such legal impediments compound the difficulties faced by these families.
- 70 Abbey Cohen, Child Care Policy and Legal Consultant.
- 71 California Code of Regulations, Title 22.
- 72 Health and Safety Code Section 1596.750.
- 73 Community Care Licensing (CCL) no longer needs to grant exceptions in order for children with disabilities to use certain postural supports and adaptive equipment in child care. This statement clarified regulations that indicate that CCL must approve in advance the use of postural supports and protective devices, although no medical procedures are involved and such devices pose no clear threat to health and safety. Consequently, no one using these supports now need be dissuaded from inclusion by the lengthy exception process.
- 74 Title 22, Section 101419.2, California Code of Regulations.
- 75 California Welfare & Institutions Code Section 4500 et seq.
- 76 California Welfare & Institutions Code Section 4685(c) (1).
- 77 34 CFR Section 303.18.
- 78 Title 17 CCR Section 52106[b][6][B][1].
- 79 Education Code Section 56441.3 (3).
- 80 Education Code 8250.5.
- 81 Education Code Section 8212.
- 82 MPP 42-713.24.



Discussion

Background

This study explored a number of issues pertaining to inclusive child care in California, including the potential impact of several sociocultural variables on families' reported access to quality, inclusive child care for young children with disabilities and other special needs. Findings related to the original research questions are discussed.

Children With Disabilities and Other Special Needs

The first objective of this research was to determine how many and which children with disabilities and other special needs were served in the state. After engaging in discussions with state agencies that serve or administer programs for children with disabilities and other special needs, it was clear that current data systems in California are inadequate to accurately determine who the children with disabilities and other special needs are. Only children with “identified” disabilities or special needs are reported to the state by the regional centers (serving children birth to age 3 in California’s Part C program of the Individuals with Disabilities Education Act [IDEA]) and by school districts providing special education services for children birth to age 5 under Part B of IDEA. Consistent, reliable data matched to the definition of “disability and other special needs” adopted for this study were only collected on children who are served by one of these two agencies.

Based on the definition used in this study, it was impossible to determine an exact unduplicated count of children with disabilities and other special needs. We do know how many children have disabilities or are at risk for disabilities who have Individualized Family Service Plans (IFSPs) or Individualized Education Programs (IEPs) and are being served by regional centers or special education. However, this is also not an unduplicated count, as there may be approximately 3,000 children ages birth to 3 who are eligible for both regional center and special education services and are counted by both systems.

Researchers also know the number of children with disabilities and other special needs enrolled in child care programs as reported by surveyed child care providers. Nevertheless, results from this study indicate that existing data systems in California cannot provide exact information regarding the categories and numbers of young children with disabilities and other special needs across the service systems involved.

While it was expected that child care providers would report serving a larger number of children with disabilities and other special needs than special education or regional centers report serving because of the broader category of children who have “special needs”, it should be noted that child care providers are not required to report this information to the state at this time. Even subsidized child care programs and providers who may receive a higher reimbursement for a child with a disability are required to keep documentation of the child’s disability, but not to report to any state agency the number

of children served or the types of disabilities they may have. Some child care Resource and Referral (R&R) or Alternative Payment Program agencies maintain this data locally.

There is a model for this type of systematic data collection. Head Start programs report annually on the number of children with disabilities served and the types of disabilities they have as well as on the specific services children are provided and by whom.

Challenges and Strategies for Families and Child Care Providers

In general, when inclusion works in child care, it does so based on personal relationships. This is a recurring theme that has been emphasized repeatedly in this report. Programs and caregivers who receive adequate support and training from agencies that work specifically with families and children with disabilities and other special needs, and that collaborate and communicate effectively with one another and with the families they serve, can create and maintain quality inclusive programs that nurture and benefit young children with typical and atypical development alike.

By nurturing collaborative relationships among staff, families, and support agencies, early care programs can effectively transform their developmentally and age-appropriate curriculum into one that is also individually appropriate to meet the unique needs of young children with disabilities and other special needs. Teachers and caregivers in inclusive programs can also be trained and given adequate support to implement specific strategies that facilitate interactions among all children in their programs⁸³ so that those with disabilities and other special needs are effectively included. In addition, as researchers discovered through various data sources used in this study (i.e., surveys, questionnaires, focus group discussions, and interviews), relationships are critical to successful inclusive child care for providers, families, and young children alike.

Families may also require other support services to ensure access and the continued success of their children in child care.⁸⁴ These services may include respite care, counseling, assistance in coordinating their children's services, and, for some, consultation with an advocate who has adequate knowledge of relevant laws. The IDEA and the Americans with Disabilities Act (ADA) are two major pieces of legislation that potentially have the biggest impact on families with young children with disabilities and other special needs. However, findings from this study suggest that most child care providers and parents receive no training and information regarding these statutes.

Most child care providers know in general terms that they must comply with the ADA and make reasonable accommodations for children with disabilities and other special needs. However, successful inclusion is less dependent upon knowing the law and more dependent upon: (1) caregiver comfort with children with disabilities and their families; and (2) knowledge about how to adequately meet the needs of these children. As child care providers' knowledge about care of children with disabilities increases, so does their reported level of comfort in giving families the skills needed to identify community resources, supports, and training programs. Developing positive attitudes about disability are shaped by positive experiences.

Further exploration of these issues could provide some insight regarding which specific factors influence providers' level of comfort. Findings in this study suggest that level of comfort may in large part be attributable to the amount of training and supported experience in working with young children with disabilities as well as knowledge of the laws as they relate to requirements and expectations of care providers.

Impact of Sociocultural Variables on Access to Child Care

Researchers examined the potential effects of socioeconomic status, ethnicity, language, education level, and geographical location on families' access to inclusive child care, and predicted that many, if not all, of these factors would significantly affect or be related to families' access to inclusive child care.

Examining differences in access to inclusive child care by income categories, those parents with incomes from \$50,000 to \$75,000 reported having more difficulty finding and keeping child care than parents from other income categories. For those parents with incomes \$10,000 to \$15,000, affordability was an issue. Although not statistically significant, these observed differences may warrant further investigation. Perhaps a greater number of diverse programs are available for families with lower incomes (e.g., Early Head Start, Head Start, CalWORKs), therefore facilitating access to child care for low-income parents. Likewise, one potential reason why families with higher incomes reported more difficulties in finding child care may have been due to not being eligible for existing financial support services for child care or to a lack of information about access to such services. Many middle-income and upper-income families are caught in situations where they earn too much money to get financial

assistance, but not enough to pay for services. Still another possibility might be the greater number of families in those income brackets who require child care competing for limited program slots for all children.

In addition, a larger percentage of parents with smaller incomes had difficulty finding care for hours needed and finding care close to their home or work. In contrast, half as many parents with higher incomes had difficulty finding care due to hours or proximity to work and home. For these parents, the most frequently cited reason for their difficulty in finding care was their worry about leaving their child. Finally, parents from lower income categories reported refusal of or dismissal from child care due to their child's health, disability, or other special need, as compared to parents within the \$25,000 to \$75,000 categories, to whom lack of experience with their child's specific disability was the rationale given for refusal of or dismissal from child care.

An examination of access to child care by ethnic group categories was difficult due to the small number of African-American and Asian American parents who responded to these specific questions. Generally speaking, there seemed to be no major differences in the percentage of parents by ethnic category who had difficulty finding or keeping child care.

In examining the impact of primary language spoken in the home on access to inclusive child care, the main finding was that parents in homes in which English was the primary language did not have as much difficulty finding and keeping child care in contrast to parents in homes in which Spanish or Chinese was the primary language. However, affordability was again a primary reason for difficulty of access across all categories.

Statistically significant differences were found when parent education levels were compared. Parents with more education reported more challenges in securing inclusive child care than did parents with less education. Mothers and fathers in this study with some high school education found it less difficult to find child care than did mothers and fathers with a college degree. Perhaps those with less education were not aware of the choices in child care available to them or of "best practices" in early care, and therefore did not attempt to seek out potential options for their children. It could also be that families with less education were also in lower income brackets and, as stated earlier, more programs may be offered to low-income families (e.g., Head Start). While consideration of causes still involves speculation, survey responses showed that the primary reason for

having difficulty accessing quality inclusive child care was affordability, regardless of educational level.

Although results were not statistically significant, parents in urban areas reported more difficulty obtaining child care than did parents in more rural areas. One possible reason for this finding could be that urban areas may contain a greater number of children requiring services, so some providers may have more choices in who they accept or reject from their programs, or they may reach their maximum enrollment quickly. On the other hand, rural and suburban areas may be less congested, and the demand for child care not so great, thereby creating many options and available “slots” in child care programs.

While parents in urban areas reported the most difficulty in obtaining quality child care, when examining why parents in any geographic area had difficulty finding child care, a primary reason across geographic settings was cost. While more of a concern in rural areas than anywhere else, cost remained a consideration in urban and suburban areas as well. Cost, however, was not the only barrier that parents encountered. In urban area, the nature of the child’s disability was the most frequently cited reason for children being refused or dismissed from child care; in rural areas, the lack of experience caring for children with disabilities and inadequate staff training were problematic.

In conclusion, data obtained in this study in part supported initial hypotheses and expectations, although there were a few interesting surprises. The effects of sociocultural variables such as social class and parent education were not as originally expected, but triangulation from other sources of data helped clarify the study’s results and provide possible explanations. Reports from parents and care providers in this study were consistent with findings outlined in the Map to Inclusive Child Care (Map) Project, but also added to the research team’s existing knowledge and understanding of these important issues. Some important trends were apparent in the analyses, and although many were not statistically significant, they nevertheless warrant further investigation. Future studies might probe into the effects of social class on families’ access to quality inclusive child care, but in a more tightly controlled, experimental design. A clearer picture of how various sociocultural variables impact families’ experiences with the system seems critical to building culturally and individually sensitive relationships that are essential to successful family-professional collaboration and to meeting the needs of all young children.

Methodological Limitations

While researchers on this study do not believe the results would vary significantly had it been designed and conducted differently, it is important to note that given the various methodological limitations in this exploratory study, results must be interpreted with caution. This study was not meant to be a tightly controlled experiment and, therefore, did not include strict standardization of instrumentation, data collection, and procedures.

It was determined within the initial design to create surveys that were consistent with those developed for the Map Project. The surveys, although piloted, were not subjected to psychometric statistical tests and validation. Several of the questions on the surveys were also written and posed in a manner that did not prevent duplication of responses.

Sampling of family surveys was neither random nor controlled to prevent duplication of responses. Neither were controls designed into the surveys and their distribution to prevent various confounds that potentially increased “error” in the data. For example, data analyses of the surveys did not differentiate between respondents who were both child care providers and parents of a child with special needs and those who completed surveys or questionnaires. Neither were there controls for overlapping data from respondents who participated in the focus group discussions and who also completed surveys/questionnaires.

Attrition, failure to complete all survey items, refusal to participate, and other actions that resulted in surveys being unusable were also not recorded. For this reason, it was difficult to determine whether the study’s results were in part due to confounding influences among respondents who opted to participate in the study; those who chose not to participate; and those who initially agreed to participate, but failed to complete the process. The same can be said for those selected to participate in the focus groups. Sampling required more structured planning with specified criterion for participants. Focus group participants ranged from families currently being served in the system, those served several years prior, and those not involved in any system at all — including child care.

83 Odom & Brown, 1993; Bruder, 1998.

84 Whitney, Groginsky, & Poppe, 1999.



Recommendations for Practice and Future Research

Summary

Child care in California and across the nation is in a state of crisis. Poorly paid staff, inadequate funding to meet program demands, and inconsistently monitored preparation standards for administrators and staff are but a few of the problems that plague child care today. Parents who have difficulty understanding and negotiating the complexities of the system often lack sufficient support. Not only does the general state of child care warrant attention, but additionally, specific barriers to child care for children with disabilities and other special needs persist.

It is true that some promising practices are beginning to emerge at both the state and county levels as a direct result of California Children and Families Commission (CCFC) activities. The *Barriers to Inclusive Child Care* study found that many counties have initiated activities that have the potential to positively impact the lives of children with disabilities and other special needs and their families. A broader range of agencies and programs that serve young children, that previously had not participated in local decision making, are joining in planning discussions with families, child care providers, and specialized service providers at both state and local levels.

However, there is currently no mechanism for evaluating and monitoring the effectiveness of efforts by all agencies and programs charged with providing or administering services for children, including those with disabilities and other special needs. This precludes the implementation of effective practices and constrains

the ability of state policymakers to make informed decisions about where to invest increasingly limited resources. Without such a mechanism, and in lieu of an explicit state requirement, individual counties can be expected to continue funding and supporting those activities that are largely driven by the pressures of local politics. In the absence of any change in policies and practices, current forces are predicted to remain in place, and children with disabilities and other special needs will continue to be overlooked or addressed as an afterthought within the general system of early care and education.

It is hoped that this report will contribute information and recommendations that can inform the discourse at both state and local levels and ultimately lead to positive change.

Recommendations

The following recommendations are offered to address the major barriers to inclusive child care identified in this study. These recommendations were intended to enhance both access — defined as entry to child care — and success — defined as the ongoing maintenance of appropriate child care once it is found. Some of the recommendations and subsequent actions needed are under the purview of the California Children and Families Commission (CCFC), while others will best be addressed in collaboration with other state agencies, county commissions, or other key stakeholders.

Recommendation 1:

Ensure that policies and practices of CCFC (Proposition 10)-funded activities support and enhance equal access to child care for all children, including those with disabilities and other special needs.

- Develop and implement an infrastructure to link child care and families with specialized services. This can be done through current and future commission initiatives.
- Require training for all individuals working within systems serving children age birth to 5 years in relevant laws as part of any personnel development initiatives developed or funded by the CCFC. This should include the Americans with Disabilities Act (ADA), Unruh Civil Rights Act, and the Individuals with Disabilities Education Act (IDEA), and the training should be presented in partnership with state agencies that provide oversight and compliance monitoring.

Recommendation 2:

Increase dissemination of effective information to targeted audiences such as families, child care and specialized service personnel, and policymakers to improve access to and success in high-quality, appropriate child care.

- Provide support for the development of a document that reviews potential sources of funding for child care and information on how families can access services and supports for their children with disabilities and other special needs in child care settings.
- Ensure that CCFC media presentations, publications, and other materials, especially those that address diversity issues, reflect children and adults with disabilities and are culturally sensitive.
- Provide support for the development and dissemination of written materials and multimedia information in appropriate literacy levels and languages on legal rights and responsibilities of parents and providers related to children with disabilities and other special needs under relevant laws (e.g., ADA, Unruh Civil Rights Act). Additionally,

provide support for coordinating available options in the community for legal assistance to the parents, enabling them to exercise their rights of access to child care.

- Ensure that CCFC publications aimed at parents provide information about child care as well as specialized service programs.

Recommendation 3:

Support meaningful collaboration among early education, child care, specialized services, and family support systems to ensure that policies and practices reflect quality standards for inclusion of children with disabilities and other special needs in family, educational, and community settings.

- Require CCFC-funded projects to specifically collaborate on activities that enhance and improve opportunities for children with disabilities and other special needs to participate in early care and education programs.
- Promote and fund local collaboratives that include representation from local Proposition 10 Commissions, Community Care Licensing, regional centers, special education and early intervention, child care centers, family child care associations, Early Start family resource centers/networks, resource and referral agencies, local child care planning councils, and families of children with disabilities and other special needs to examine best practices and to develop protocols and guidelines.
- Fund and/or promote interagency and multidisciplinary training opportunities.

Recommendation 4:

Support legislation to improve access to and success in child care programs for children with disabilities and other special needs by amending statutes and policies that impede the inclusion of these children in child care programs.

- Support efforts to amend codes affecting Community Care Licensing, California Education Code, California Early Intervention Services Act, Lanterman Developmental Disabilities Services Act, Health and Safety, and other related statutes that include barriers to inclusive child care.
- Support the enforcement of existing regulations through information technical assistance that promote the inclusion of children with disabilities and other special needs in child care programs.
- Support the resolution of inconsistencies between state laws and regional center child care policies by convening forums or workgroups.

*Recommendation 5:***Promote minimum training requirements and standards of practice for all personnel serving children with disabilities and other special needs, including child care, specialized services, family support, and school readiness.**

- Support the establishment of agreements among community colleges, universities, and other training institutions to help ensure high-quality training for child care providers, specialized service providers, and families.
- Ensure that CCFC (Proposition 10)-funded activities include effective strategies for working with children with disabilities and other special needs as a component of any training or professional development activity.
- Support the development and delivery of multiple forms of training for all system personnel in effective practices and legal rights and responsibilities under relevant laws that affect children with disabilities and other special needs.

*Recommendation 6:***Support statewide policies and strategies for data collection that enable ongoing and long-term evaluation and monitoring of the need for and use of child care by children with disabilities and other special needs for service planning and funding purposes.**

- Support statewide policies that improve the collection of data across systems related to children with disabilities and other special needs.
- Ensure that data collection systems solicit and apply information about children with disabilities in all aspects of Proposition 10 data efforts so the needs of these children can be addressed in any policy developed from such information.
- Consider development of demonstration sites to pilot, implement, and evaluate data systems that cross current agency collection methods and then evaluate effectiveness.

*Recommendation 7:***Provide funding for additional research on the needs of children with disabilities and other special needs, their families, and the systems that serve them.**

- Investigate the relationship between child care providers and pediatricians, other health care providers, and specialized service providers regarding the identification, assessment, and provision of services for children with disabilities and other special needs in community settings.
- Examine the impact of child care programs with effective practices for children with disabilities and special needs to assess outcomes.

Conclusion

Historically, when states and local communities have designed quality child care for children, the needs of the disability community have been overlooked from the initial program development stages. Today, with unprecedented attention being focused on the benefits and cost effectiveness of quality early care, opportunities to affect change for both children who are developing typically and children who have disabilities and other special needs are emerging at state and county levels.

While research on children with disabilities and other special needs in child care is limited, experts believe that equal access for these children to child care and specialized services within the child care setting is essential. In addition, early access to appropriate services and early intervention has been proven to improve developmental outcomes for children with disabilities or special needs. In spite of this evidence, current indicators, including the results of the *Barriers to Inclusive Child Care* study, suggest that child care systems do not always address the individual needs of these children.

In many ways, this study produced more questions than answers; therefore, the need for ongoing research on children with disabilities and other special needs who are in child care remains critical. The ultimate goal of the California Children and Families Commission in commissioning this study is to contribute to the creation of a more unified system of policies and practices — a system that will provide quality child care for *all* California children.

Promising practices are beginning to surface. Many counties now include representatives from their populations with disabilities and other special needs in discussions and strategic planning, and agencies and programs that serve these young children and their families are beginning to participate in policy-related decisions. This sharing of knowledge and resources will improve local capacity to create potential strategies for successfully addressing the concerns of both families and child care providers.

Child care has become a fact of life for the majority of children and families in California. Therefore, quality child care must be acknowledged and supported as one of many systems that benefits every child and family and contributes to healthy communities. However, what constitutes quality child care for all children, by its inherently undifferentiated nature, is not necessarily good for children with disabilities or special needs. Quality child care for children with disabilities and other special needs is based upon care that addresses the individual needs of every child. Improving child care for children with disabilities and special needs will not only benefit those children, but will positively impact families, schools, communities, and society as a whole.