# Equity and Disparity in Access to Services:

## An Outcomes-Based Evaluation of Early Intervention Child Find in Hawai`i

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Young children with developmental delays can benefit from early intervention under Part C of the Individuals with Disabilities Education Act (IDEA) only if they are identified and served before the age of 3 years. IDEA mandates Child Find activities to promote access to Part C services, that is, to promote identification of children and referral for and enrollment in services. An evaluation of Hawai`i's early intervention Child Find examined the equity of access to referral and enrollment across various subpopulations. Reassuring results were obtained for low-income and immigrant households, but access for children from military families appeared to be less equitable. The study provided conflicting evidence with respect to access for children whose parents spoke little English. Uninsured children experienced the greatest disparity in access. Recommendations to improve Child Find services include expanded outreach among military families and families whose children lack health insurance. Future evaluations of equity would be facilitated by more complete statewide data systems and by qualitative studies of the perceptions of referred families and referring professionals. Other states are encouraged to undertake similar evaluations.

Early intervention (EI) can improve the functional abilities of infants and toddlers with developmental delays through the provision of therapeutic and related services to the child and a variety of supports for families (American Academy of Pediatrics, Committee on Children with Disabilities, 1994; Garland, 1981; Guralnick, 1997). In recognition of the potential benefits of early intervention, in 1986 the U.S. Congress authorized and funded Part H of the Education for All Handicapped Children Act of 1975 (amended 1986), which is now Part C of the Individuals with Disabilities Education Act of 1990. Under Part C, the states have broad latitude in defining the eligible population and structuring their service systems, but they are required to implement certain components, including a Child Find function to bring eligible children into services. Child Find is often narrowly conceived as a specific set of outreach activities for identifying eligible children through increased awareness of disabilities in young children and the availability of services (Bernstein, 1993; Wright, 1992). Children and families can benefit from EI (Part C) programs only if they are identified, found to be eligible, and served before the child is 3 years old. Consequently, we conceptualize Child Find more broadly as the entire range of activities necessary for this process (i.e., public awareness, identification, referral, eligibility determination, and enrollment). Figure 1 is a graphic representation of these processes.

A democratic society strives to serve all its citizens without bias regarding demographic characteristics. In recent years, the field of public health has become increasingly aware of and attentive to the issue of disparity in access to health care and health outcomes across certain demographic subpopulations (Kelley et al., 2004). Disparities in access represent a failure to enroll eligible program participants, depriving them of the benefits of program services. Disparities have been documented for several subpopulations including those defined by minority ethnicity, low income, recent immigration, and limited English proficiency (Brown, Wyn, & Ojeda, 1999; Egede & Zheng, 2003; Granados, Puvvula, Berman, & Dowling, 2001; O'Malley, et al. 2001; Saha, Arbelaez, & Cooper, 2003; Shi & Starfield, 2001; Weinick & Krauss, 2000). The study reported here addresses the research question of whether demographic subpopulations, which have limited access to health care in general, have equitable access to EI services in Hawai`i (see Note 1).

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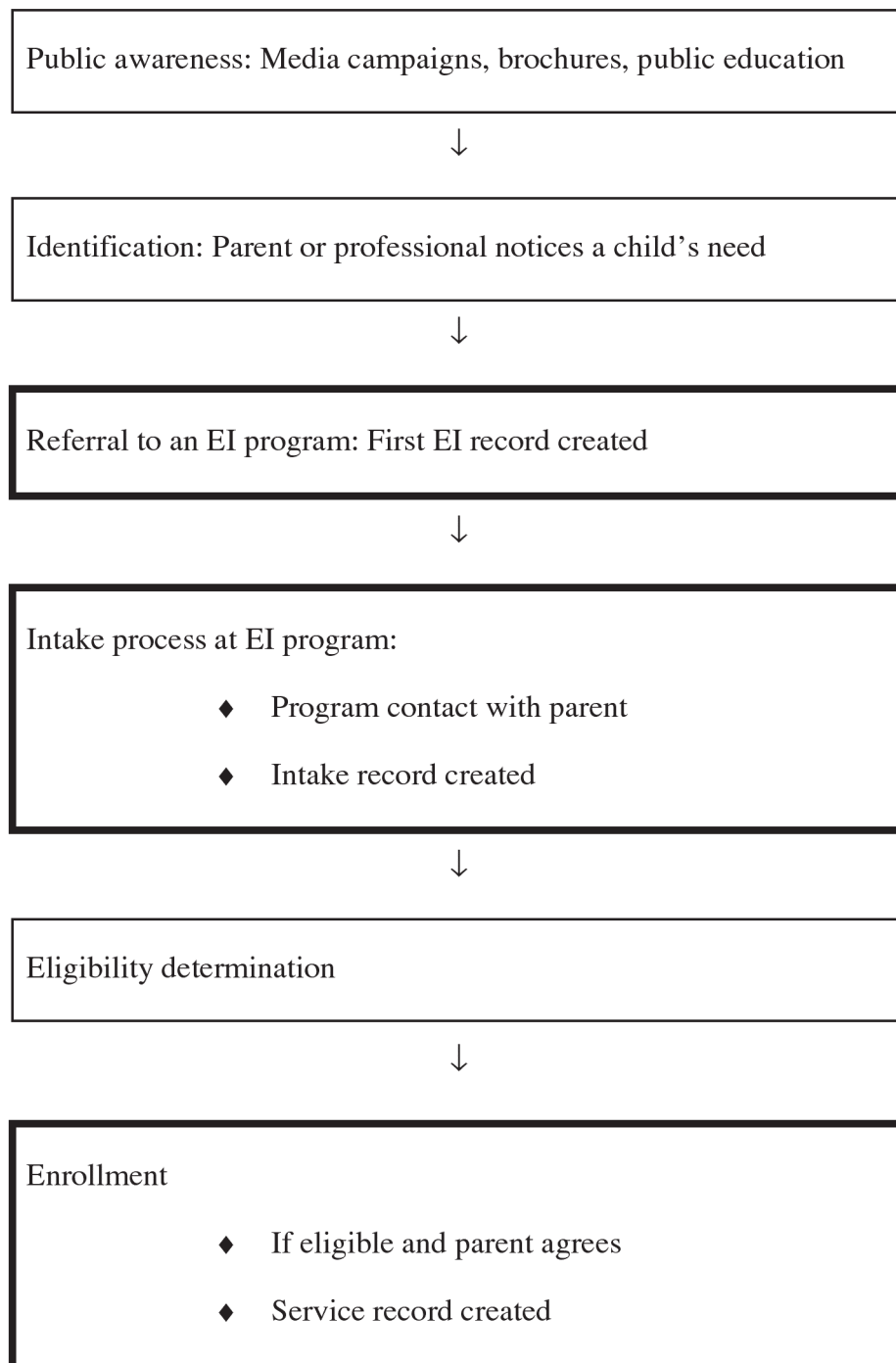
| Public awareness: Media campaigns, brochures, public education |
| --- |

↓

| Identification: Parent or professional notices a child's need |
| --- |

↓

| Referral to an EI program: First EI record created |
| --- |

↓

Intake process at EI program:

♦ Program contact with parent

♦ Intake record created

↓

Eligibility determination

↓

Enrollment

♦ If eligible and parent agrees

♦ Service record created

**FIGURE 1.** Child Find processes. Darkened borders indicate processes studied.

The need for equitable EI access is especially urgent because the same family demographics associated with elevated risk of developmental delays and later academic failure (e.g., Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Fujiura &Yamaki, 2000; Institute for Educational Leadership, 2003) have also been linked to decreased access to services (Kogan et al., 1995; National Center for Health Statistics, 1998; Taylor & Brown, 1996). Because EI is designed to improve developmental outcomes and lay the foundation for academic success, children with these risk factors must have equitable access to EI.

The literature contains few—if any—comprehensive evaluations of EI Child Find equity across a variety of

subpopulations. States report counts of either referred or enrolled children by ethnicity, but these reports do not examine equity in comparison to the ethnic population profile of the particular state, and they do not compare the number of children referred to the number actually enrolled in services. Ethnicity alone may not be the most telling predictor of disparity. Demographic variables, such as SES (Holohan, Dubay, & Kenney, 2003; National Center for Health Statistics, 1998) and English proficiency (Weinick & Krauss, 2000; Yu, Nyman, Kogan, Huang, & Schwalberg, 2004), often underlie ethnic disparities.

# CHILD FIND IN HAWAI'I

From 1996 to 1998, the Hawai'i Department of Health conducted an outcomes-based evaluation of its early intervention Child Find. The evaluation was guided by a group of stakeholders that consisted of parents of children with special needs, physicians, EI providers, and policymakers. These stakeholders were motivated to improve Hawai'i's EI system and recognized that the first step was conducting a needs assessment to identify any gaps and barriers in existing services. Acknowledging that Child Find must occur before other EI services can be implemented, they focused the evaluation on this aspect of the EI system. In response to the mounting evidence of disparity in access to health care, and the absence of related research on EI services in particular, the group designed an evaluation that examined equity in access to EI services in Hawai'i across several subpopulations.

## Study Subpopulations

**Low-Income Families.** Poverty is one of the strongest predictors of early developmental delay (Chipungu & Bent-Goodley, 2004; Fujiura & Yamaki, 2000; Lee, Sills, & Oh, 2002; National Center for Health Statistics, 1998). Low income for a family is also associated with decreased access to health care (Davidoff, 2004; National Center for Children in Poverty, 2001).

**Uninsured Children.** Lack of health insurance is associated with decreased access to health care (Kogan et al., 1995; Wirthlin Worldwide, 2001). It is also associated with poorer overall health (Urban Institute, 2002).

**Immigrants and Parents with Limited English Proficiency.** Like many border states, Hawai'i has a large and growing immigrant population, which in 2000 was 4.1% of the total state population (U.S. Department of Commerce, Census Bureau, 2000). From 1990 to 1999, there was a net international migration increase of 54,227,

predominantly from Asia and the Pacific (69% of all new immigrants in 2000), despite a general population decrease of 77,268 (Hawai'i Department of Business, Economic Development, and Tourism [HIDBEDT], 1999, 2002). As in most states, recent immigrants to Hawai'i face the challenge of establishing themselves economically and socially, often without English language skills. Since the federal welfare reform of 1996, national data have demonstrated that immigrants and their children have far less access to health care than do citizens (Ku & Matani, 2001). Various barriers to service utilization, including language incompatibilities and a lack of familiarity with host culture mores and available services, have been blamed for these lower rates of service utilization. Research has documented that children of non-English–speaking parents experience barriers to accessing (a) routine and preventative health care (Weinick & Krauss, 2000) and (b) services for special health-care needs (Yu et al., 2004). Although some immigrants have limited English proficiency, others arrive with fluent English skills, and some long-time residents have learned little English.

**Military Status.** A large military presence in Hawai'i brings in many young families for 3-year tours of duty. These families may lack stable family and friendship support circles. The possible resulting estrangement from the local community and the high rate of mobility may interfere with access to social services, especially EI services, which are available only for the short interval from birth to age 3.

**Homelessness.** Homeless families with young children are a growing population with multiple risk factors for developmental delays (Karr, n.d.; National Coalition for the Homeless, 1996). Such families are also more likely to elude detection and follow up than children with more stable lifestyles (Taylor & Brown, 1996).

## Definition of Access

Access to EI may be defined in two ways. At the most basic level, *access* involves referral to EI: If physicians, childcare providers, parents, or other adults do not make an initial connection between an eligible child and an EI program, that child will not receive EI services. This initial connection, by which an EI program learns about a potentially eligible child and how to contact the child's parent or guardian, is called *referral*. However, referral alone does not convey the benefits of EI services.

As Figure 1 shows, there are three steps between referral and receipt of services. First, if the child was referred by someone other than his or her parent, the program will need to establish direct contact with a parent (or guardian) to describe available services and how

to enroll in them and to determine whether the family is interested in receiving services. Occasionally, parent contact information provided with the referral is not adequate, and contact is never made. Second, the EI program must determine the child's eligibility under state criteria. This process typically involves an assessment of the child's development. If parents do not agree to an assessment or fail to attend scheduled assessment opportunities—and, of course, if the child is found to be ineligible—the child will not receive EI services. Third, EI services can be provided legally only under an Individualized Family Services Plan (IFSP) completed by both staff member and parents. If the plan is not completed, services cannot be provided. For this study, we defined *enrollment* in EI as completion of an initial IFSP. Access to enrollment involves completion of parent contact, eligibility determination, and an IFSP.

The present study of equity addressed both aspects of access. We asked whether children from low-income, immigrant, non-English–speaking, military, and homeless families are referred and enrolled for services in proportion to their estimated prevalence in the state population.

## METHOD

A feasibility study preceding the evaluation listed available data sources and their contents. The authors of the equity evaluation used two existing data sources (paper intake records and a statewide electronic management information system database, or MIS) and developed one additional method for collecting data not available from existing sources. Each subpopulation of interest was studied through analysis of one or more of these data sources

(see Table 1). In this section, we discuss the metric used to evaluate equity, provide some background on the context of EI program data generation in Hawai'i, describe each data source, and outline methods specific to each subpopulation. The section concludes with a description of data analysis procedures.

### *Choice of Metric for Equity*

An equitable access system is one in which an eligible child has the same opportunities for access regardless of his or her demographic characteristics. Ideally, equity would be measured by comparing numbers of children served with numbers of eligible children in each subpopulation. Unfortunately, prevalence of the wide variety of special needs reflected in Hawai'i's EI eligibility criteria is unknown, even for the population at large. Nationally and locally, reported disability "prevalence" rates are almost invariably based on children served, providing no basis for addressing issues of access. A simplifying assumption was therefore necessary: The metric of equity used here assumes that the prevalence of EI eligible conditions is evenly spread across all subpopulations and therefore that the proportion of referred or enrolled children in each subpopulation should approximate the proportion of the subpopulation among the public at large. Following the example of Pandiani, Banks, Branley, Pomeroy, and Simon (2002), we selected percentage as the choice of reporting metric. Equity is evaluated by comparing observed proportions to total population proportions for each demographic subgroup. Thus, if X% of Hawai'i's population is poor, and X% of children referred to or enrolled in EI are poor, we would conclude that access is equitable with regard to income.

TABLE 1. Study Subpopulations, Data Sources, and Sample Sizes

| Subpopulation | Data source | Sample size | |
| --- | --- | --- | --- |
| | | Referral | Enrollment |
| Low-income | Intake records at EI Program (12/31/93–6/30/96) | 161 | 96 |
| | Study-specific records of phoned referrals | 286 | *na* |
| | MIS | *na* | 911 |
| Uninsured | Intake records at EI Program (12/31/93–6/30/96) | 161 | 96 |
| | MIS | *na* | 911 |
| Immigrants | Study-specific records of phoned referrals | 286 | *na* |
| Limited English proficiency | Study-specific records of phoned referrals | 286 | *na* |
| | MIS | *na* | 911 |
| Military dependents | Study-specific records of phoned referrals | 286 | *na* |
| | MIS | *na* | 911 |

*Note.* EI = early intervention; MIS = management information system.

## Context and Study Sites

The early intervention system for children with developmental delays operates through two types of programs. Infant/Toddler Development Programs (ITDPs) generally serve those children who have delays in two or more domains. These programs also serve geographically distinct areas in Hawai'i, except in the major urban area of Honolulu, where families may have a choice between programs. Approximately two thirds of the state's population resides in urban Honolulu. The Public Health Nursing Branch (PHNB) serves children with a medical condition or a single domain of delay through geographically defined section offices.

## Data Sources

Data were collected from 1996 to 1998 in urban Honolulu, as well as from various rural sites, of which one is on the island of O'ahu and four are on the "neighbor" islands. When we collected data directly from rural EI programs, we asked each program to provide only one of the three types of data described next, to minimize the impact of data collection on staff members at these smaller programs.

Data Source 1: Intake Records. Referrals to EI programs were made either directly to a program or were mediated by a telephone information and referral service that receives and records the referral, selects the appropriate EI program for the child, and forwards referral information to the program. When a referral is made, the receiving program staff records information about the referral on an intake form. The format, content, and consistency of this information vary among programs; no program systematically records immigrant or military status, degree of English proficiency, or homelessness.

We requested access to intake records from nine ITDPs and two PHNB sections randomly selected from all such programs. The two selected urban ITDPs refused access to their records due to managerial concern about confidentiality in one case and managerial turnover in the other. We selected intake records from the remaining seven programs. Starting from the most recent referral, we examined up to 40 intake records at each program site, attempting to select the 20 most recent direct referrals and 20 indicating assistance from the telephone service within the past 2 years. At one program, 44 records were selected and retained to permit different analyses, due to the number of records with missing data.

These intake records included data on children's insurance coverage. For insured children, type of insurance served as a proxy variable for income, with a binary categorization of "low-income" (public insurance) or "higher income" (private insurance). During the period in question, families in Hawai'i with income at or below 185% of the federal poverty level were eligible for public insurance. Conservatively, we included children with no insurance among the "higher income" group when examining equity of access for children from low-income families. Referral dates ranged from 1994 to 1998, but only 1997 data were used in this analysis, because 1997 data reflected referrals over an entire year more completely than data for other years, thus allowing a comparison with published annual data.

Data Source 2: Study-Specific Information Collected at First Referral. At the initial referral, program staff usually record little information, due to hesitancy to ask personal questions at first contact, uncertainty as to disposition, and time pressures. Permanent records contain much more information for *enrolled* children; this study of equity starting at referral required collection of study-specific data. We wrote and piloted questions to allow staff members receiving referrals to record data on the demographic subgroups of interest. We individualized the questions for each program based on intake practices and the willingness of staff members to ask specific questions. Staff members declined to ask families about homelessness due to its stigma and the potential refusal of services by needy families. They agreed to ask families at referral about income and household size, immigrant status, need for interpreter, and insurance. Insurance information was used to identify indicated military dependents, as all military families are covered through Department of Defense health insurance.

At each program, staff members receiving phone referrals during the data collection period introduced the study to callers, solicited consent to proceed, asked the additional questions, and completed data collection forms created for this purpose. Programs receive referrals relatively infrequently and at unpredictable days and times; our resources did not support the outplacement of study staff at programs across the state to directly observe program staff collecting and recording data. Phone interviewing could not be audiotaped because program staff members were unwilling during initial contact to make extraneous demands that might deter families from enrolling in services. Although program staff members received brief initial training and a script for asking the additional questions, measures of consistency of questioning or reliability of data recording were not available.

Data were collected over a period of 8 months from PHNB and the telephone service and over 11 months for the ITDPs. To create 12-month data comparable to annual Hawai'i Census counts, we multiplied our counts by 1.5 and 1.09, respectively.

Data Source 3. Analysis of Statewide Early Intervention MIS. The MIS database contained records of more

than 6,000 children who were enrolled in EI at any time between 1990 and 1999 and whose parents signed a release to permit the transfer of data to the statewide MIS. To create a data set comparable to Data Sources 1 and 2, we selected for analysis the records of 912 children referred in 1997. We selected and analyzed records that included information on the need for an interpreter and on insurance. The MIS did not contain fields for income, immigrant status, or homelessness.

## Data Analysis Procedures

We analyzed data with the Statistical Package for the Social Sciences (SPSS, version 11.5), from which frequencies, totals, and percentages were derived. For categorical comparisons, we used GraphPad InStat to calculate chi square with Yates' correction for continuity (Graphpad Software, 2000). An alpha level of .05 was considered significant.

As a measure of effect size, we report for each analysis the relative risk (RR) associated with the chi-square comparison. RR provided a measure of the extent to which the subgroup under consideration (e.g., uninsured children) was referred or enrolled more or less often than would be expected, given the state prevalence of that subgroup. RR was calculated as the proportion of the subgroup in question among the observations, divided by the proportion of the subgroup among the population at large. This measure is widely regarded as appropriate for determining the effect size for cohort and cross-sectional studies (Alderson & Green, 2003) and has been used in health-risk assessments (e.g., Wallace, Denk, & Kruse, 2003). In the Results section of this article, the RR reported is calculated as the "risk" for referral or enrollment, rather than the risk of not being referred or enrolled. For each subgroup analysis, we calculated a 95% confidence interval (CI) around the percentage of that subgroup in our sample, according to the procedure for single proportions (Wilson, 1927). The CI is the range of values within which the percentage is expected to fall at the stated confidence level.

## RESULTS

### Low-Income Children: Access to Referral

**Analysis of Intake Records.** Table 2 presents data for the insurance category. Data from Hawai'i's public insurance provider (A. M. Tran, Hawai'i Department of Human Services, personal communication, August 13, 2004) indicated that 18,574, or 38.7% of the total number of children ages 3 years to 5 years (HIDBEDT, 2000), were enrolled in public insurance in 2000 (these children would have been under the age of 3 in 1997, the period of intake data analyzed). Significantly more children with

**TABLE 2. Numbers and Percentages of Intake Records by Insurance Category**

| Insurance category | Referred | | Enrolled | | Not enrolled | |
|---|---|---|---|---|---|---|
| | *n* | %ᵃ | *n* | %ᵃ | *n* | %ᵃ |
| Public | 102 | 63.4 | 65 | 67.7 | 37 | 56.9 |
| Private | 52 | 32.3 | 28 | 29.1 | 24 | 36.9 |
| None | 7 | 4.3 | 3 | 3.1 | 4 | 6.2 |

ᵃPercentage of all referrals with insurance information.

public insurance (63.4%) were referred than would be expected, given the proportion of publicly insured children in the population, $\chi^2(1, N = 161) = 40.17$, $p < .0001$; RR = 1.64 (see Table 3 for comparison statistics).

**Analysis of Study-Specific Referral Data.** Of the 386 records collected, 238 (61.7%) contained data on income range and number of family members (other responders refused or were unable to answer the questions). We used the federal poverty level for 1999 (HIDBEDT, 2002) to estimate the number of referred children living in families whose income was below this level. The extrapolated full-year figures are 135 of 334 (40.4%). This is significantly higher than the proportion of poor children under age 3 years in 1997 (14.7%), based on the 2000 Census count of children ages 3 years to 5 years living in poverty, $\chi^2(1, N = 334) = 170.94$, $p < .0001$; RR = 2.75 (HIDBEDT, 2002).

### Low-Income Children: Access to Enrollment

**Analysis of Intake Records.** Table 2 displays the proportions of referred children in each insurance category who were enrolled. Comparing study data to the 2000 data from the Department of Human Services for children ages 3 to 5, we found significantly more children with public insurance (67.7%) enrolled than would be expected (38.7%), $\chi^2(1, N = 96) = 32.84$, $p < .0001$; RR = 1.75.

**Analysis of MIS.** Of 911 records containing insurance information, 432 (47.4%) indicated public insurance. Significantly more children with public insurance were enrolled than the 38.7% expected based on 2000 data: $\chi^2(1, N = 911) = 28.46$, $p < .0001$; RR = 1.23.

### Uninsured Children: Access to Referral

**Analysis of Intake Records.** In the absence of direct state data on the number of uninsured children under age 3, we used an estimate based on 2000 Census data

**TABLE 3. Study Subpopulation Comparison Statistics**

| Subpopulation | Comparison data | Data source comparison pop. % | Referral | | | Enrollment | | |
|---|---|---|---|---|---|---|---|---|
| | | | Data source | Observed %/CI | *ES*/CI | Data source | Observed %/CI | *ES*/CI |
| Low income | Publicly insured | 2000 DHS 38.7 | Intake | 63.4*/ 55.7–70.4 | RR = 1.64/ 1.46–1.85 | Intake | 67.7*/ 57.8–76.2 | RR = 1.75/ 1.52–2.01 |
| | | | | | | MIS | 47.4/ 44.2–50.7 | RR = 1.23/ 1.14–1.31 |
| Low income | < 100% 2000 federal poverty level | 2000 Census 14.7 | Study specific | 40.4*/ 35.3–45.8 | RR = 2.75/ 2.41–3.14 | | | |
| Insurance | Uninsured | 2000 Census 7.1 | Intake | 4.3/ 2.1–8.7 | RR = 0.61/ .30–1.26 | Intake | 3.1/ 1.1–8.8 | RR = 0.44/ 0.14–1.34 |
| | | | | | | MIS | 2.4/ 1.6–3.6 | RR = 0.34/ 0.22–0.51 |
| Immigrants | U.S. resident < 5 yrs | 2000 Census 4.1 | Study specific | 11.7/ 9.1–14.9 | RR = 2.83/ 2.21–3.62 | | | |
| Limited English | Speaks English: "Not at all" | 2000 Census 0.6 | Study specific | 6.8/ 5.0–9.3 | RR = 10.82/ 7.84–14.92 | MIS[a] | 3.9/ 2.6–5.9 | RR = 6.26/ 4.18–9.35 |
| | | | | | | MIS[b] | 2.2*/ 1.5–3.3 | RR = 3.54/ 2.36–5.31 |
| | Speaks English: "Not well" + "Not at all" | 2000 Census 5.8 | Study specific | 6.8/ 5.0–9.3 | RR = 1.19/ 0.86–1.63 | MIS[a] | 3.9/ 2.6–5.9 | RR = 0.69/ 0.46–1.02 |
| | | | | | | MIS[b] | 2.2*/ 1.5–3.3 | RR = 0.49/ 0.26–0.58 |
| Military status | Military dependents | 2000 Census 11.2 | Study specific | 13.3/ 10.4–16.8 | RR = 1.19/ 0.94–1.51 | MIS | 5.8*/ 4.2–7.2 | RR = 0.49/ 0.37–0.64 |

*Note.* CI = 95% confidence interval; ES = effect size; DHS = Hawai'i Department of Human Services; RR = relative risk; MIS = management information system.
[a]Figure includes only nonmissing data. [b]Figure includes missing data, assuming it represents higher English proficiency (i.e., no need for interpreter).
*$p < 0.0001$.

for children in Hawai'i under age 18 (see Note 2). Although the children with no insurance were underrepresented, this percentage did not differ significantly from the population proportion (4.3% vs. 7.1%, respectively), $\chi^2(1, N = 161) = 1.45$, $p = .23$; RR = 0.61.

## Uninsured Children: Access to Enrollment

**Analysis of Intake Records.** Only seven children without health insurance were referred to EI, and only three were enrolled. However, the percentage did not differ significantly from the population proportion (3.1% vs. 7.1%, respectively), $\chi^2(1, N = 96) = 1.73$, $p = .19$; RR = 0.44.

**Analysis of MIS.** Children ages birth to 3 years with no insurance (2.4%) were seriously underrepresented in the enrolled population, as compared to the 7.1% population estimate of uninsured children ages 3 years to 5 years based on the 2000 Census (U.S. Department of Commerce, Census Bureau, 2004b), $\chi^2(1, N = 911) = 29.37$, $p < .0001$; RR = .34.

## Immigrant Families: Access to Referral

**Analysis of Study-Specific Referral Data.** Of 350 referrals with information on immigrant status, 43 were categorized as immigrant (one or both parents had lived in the United States for less than 5 years). Extrapolated

figures for 1 year of referral data were 56 immigrant children and 424 nonimmigrant children. A comparison of the 11.7% of referrals categorized as immigrant with the estimated 4.1% of state residents ages 18 to 44 years who had resided in another country 5 years before the 2000 Census (HIDBEDT, 2000; U. S. Department of Commerce, 2000) indicated that immigrants' children were referred significantly more often than would be expected, $\chi^2$(1, $N$ = 480) = 66.98, $p$ < .0001; RR = 2.83.

## Parents with Limited English Proficiency: Access to Referral

**Analysis of Study-Specific Referral Data.** Only 24 of 377 families whose records contained relevant information indicated they needed an interpreter. Extrapolated figures for 1 full year of data collection are 35 families out of 513 families. Equity was examined first by comparing the proportion of referred children whose families indicated a need for an interpreter (6.8%) with the proportion of individuals ages 18 to 44 who reported on the 2000 Census that they spoke English "not at all" (0.6%; see Note 3). Significantly more families who needed an interpreter were referred than would be expected, $\chi^2$(1, $N$ = 513) = 300.53, $p$ < .0001; RR = 10.82. However, when we used an alternative population measure, by combining Census categories of people who did not speak English well and people who did not speak it at all, the number of referred families who needed an interpreter approximated the expected number (5.8%), $\chi^2$(1, $N$ = 513) = 0.90, $p$ = .34; RR = 1.19.

## Parents with Limited English Proficiency: Access to Enrollment

**Analysis of the MIS.** Of the 1,050 children whose records were examined, 583 contained information as to whether the family needed an interpreter. Twenty-three records (3.9%) indicated that an interpreter was needed. A greater proportion of enrolled families needed an interpreter than the 0.6% of the population ages 18 to 44 who reported that they spoke English "not at all," $\chi^2$(1, $N$ = 583) = 96.23, $p$ < .0001; RR = 6.26. When we used the alternative definition of limited English proficiency for the population measure, the 3.9% estimate did not differ significantly from the 5.8% of people ages 18 to 44 who spoke English "not well" or "not at all," $\chi^2$(1, $N$ = 583) = 3.18, $p$ = .07; RR = 0.69.

It is possible that providers more consistently record affirmative values ("need an interpreter") than negative ones. If we assume that records with no information on need for an interpreter imply that no interpreter was needed, 23 (2.2%) of 1,030 families needed an interpreter. Even using this interpretation of the sample data, families who needed an interpreter were enrolled signifi-

cantly more often as compared to Census figures for people ages 18 to 44 who did not speak English at all, $\chi^2$(1, $N$ = 1,030) = 39.37, $p$ < .0001; RR = 3.54. However, they were significantly underenrolled compared to adults ages 18 to 44 who did not speak English well or at all, $\chi^2$(1, $N$ = 1,030) = 22.85, $p$ < .0001; RR = 0.39.

## Children in Military Families: Access to Referral

**Analysis of Study-Specific Referral Data.** Of 315 children whose referral records contained information on military status, 39 had a parent who was a member of the armed forces. Extrapolated full-year figures were 59 military dependents among 444 referrals (13.3%), similar to the representation of military dependents ages 3 to 5 in the general population (11.2%) estimated from the 2000 Census, $\chi^2$(1, $N$ = 444) = 1.81, $p$ = .18; RR = 1.19 (see Note 4).

## Children in Military Families: Access to Enrollment

**Analysis of MIS.** Using insurance information as a proxy for military status, we identified 50 (5.5%) of 911 records with insurance information as military, which was compared to the population estimate of 11.2%. The proportion of military enrollments was significantly less than would be expected, based on estimates from the 2000 Census (HIDBEDT, 2001), $\chi^2$(1, $N$ = 912) = 28.73, $p$ < .0001; RR = 0.49.

## DISCUSSION

The present study demonstrated that children from low-income and immigrant families had equitable access to early intervention services. Results for children from uninsured, non–English-speaking, and military families were less conclusive.

## Methodological Issues and Limitations

The decision to evaluate equity against a standard defined as the proportion of children belonging to each demographic subgroup in the state population calculated from 2000 Census reports entailed three limitations on the rigor of the standard itself. First, these data are a snapshot of demographic characteristics in 1 year of data collection, that is, 1999 for the 2000 Census, whereas we collected data primarily during 1997. For comparability to our data on children ages birth to 3 years in 1997, we used Census data for children ages 3 years to 5 years. Some changes in the demographic profiles of these birth cohorts between 1997 and 1999—due, for instance, to im-

migration and mortality—may have introduced error, although the size of the data set and the short time period limits the magnitude of this error.

Second, the Census did not report subpopulation data specific to children ages 3 to 5, requiring the estimation procedures described in the Results section. These procedures are based on simplifying assumptions; our confidence in estimating values for children in this age range from Census reports for children ages birth to 5 years is greater than for the Census data on uninsured children and military dependents, which reflected a much wider age range.

Third, the Census asked respondents to rate their degree of English proficiency, whereas we relied on the decision of program staff members concerning the need for an interpreter. This difference reduces the comparability of our data to Census reports. These limitations may have introduced errors in analyses that we cannot estimate. However, decennial Census counts are the most reliable data source available for describing state demographics because the Census Bureau uses standardized methods and collects demographic data from more individuals for the Census than any other published source. The importance of examining equity in access to early intervention and the lack of a more comparable data source justified use of this standard in spite of its limitations.

The validity of our three data sources is limited. The accuracy of program data recording and entry are unknown. Due to logistical and political factors, we were unable to examine intake records from urban ITDPs, limiting our ability to generalize results to the entire state. However, the study-specific referral data were collected from urban ITDPs, and MIS records reflected statewide enrollments. Convergent results among data sources for low-income, limited-English-proficiency, and immigrant populations validate the use of intake records.

The reliability of our study-specific data could not be measured. We provided a written script for program personnel to use when questioning families at referral; however, due to the geographic decentralization and episodic nature of referrals, and the many different staff persons involved, we could not observe their administration of the questions. Interstaff reliability cannot be estimated. In the absence of intake records containing data on demographics associated with limited access to health care, study-specific data allowed us to at least conduct a preliminary investigation of equity for families referred to, but not necessarily enrolled in, EI programs. These limitations must be considered in the interpretation of reported results.

## Low-Income Children

Our only direct data on household income came from study-specific intake records. All other analyses used in-surance as a proxy for income. Some children who are income-eligible for public insurance are not enrolled; in 1998, the Hawai'i Department of Health estimated that 880 children ages birth through 5 years were eligible for, but not receiving, public health insurance, a small number compared to the 30,676 eligible children in that age group who were insured in 2000 (A. M. Tran, Hawai'i Department of Human Services, personal communication, August 13, 2004). These figures suggest that the number of eligible children who are not insured is not likely to change our results. Conversely, some children with significant disabilities whose families are not below the federal poverty level are covered by public insurance, but income-specific data on the number of these children were not available. The net effect on the validity of public insurance as a marker of poverty thus is unknown.

Because we compared observed insurance data to numbers of children actually covered by public insurance rather than to Census data on income, our results are not affected by these potential inaccuracies. Although the validity of extrapolating equity for publicly insured children to all poor children is unknown, consistent results from different data sources and generally robust effect sizes indicated that poor children were overrepresented in EI referrals and enrollments when compared to the proportion of poor children in the general population.

Study-specific data indicated that the poorest children, in families below 100% of the federal poverty level, were referred 2.83 times more often than expected. MIS enrollment data, which reflected a much larger and more comprehensive sample than our other data sources, indicated equitable access for children in families with incomes up to 185% of FPL with a meaningful, although not large, effect size (1.23). These results, favoring referral and enrollment of poor children, may reflect the elevated risk for developmental delay among children in low-income families (Institute for Educational Leadership, 2003; Newacheck et al., 1995).

Poor children were overrepresented at a higher rate for referrals than for enrollments. Further investigation using more comparable EI and population data and including qualitative measures could verify this discrepancy and uncover its underlying causes. For example, it is possible that higher referral rates are due to inappropriate overreferral of minority groups, as has been reported in articles on special education enrollment (Baca & Cervantes, 1989; Salend, Garrick Duhaney, & Montgomery, 2002).

## Uninsured Children

In our samples, rates of referral and enrollment of uninsured children were low. The effect sizes indicated disparity, as uninsured children were referred a third less often and enrolled as much as two thirds less often than

would be expected based on the corresponding state population. The comparison population estimate assumes that the proportion of uninsured children ages 3 to 5 is the same as the proportion under age 18. In fact, nationally, older children are more likely to be uninsured (National Center for Health Statistics, 2002; U.S. Department of Commerce, Census Bureau, 1997). We therefore are comparing study data on uninsured children to figures that are probably too high; the degree of disparity is probably smaller than our analyses imply. Nonetheless, the effect sizes obtained (RR = 0.34–0.61), together with national data on health-care access, justify concern.

In Hawai‘i, neither insurance nor income is considered in eligibility for EI, and EI services are provided at no cost to families. However, many professionals in a position to identify and refer children are unaware of this EI policy (Derrington & Shapiro, 2003). The misperception that children must have insurance to participate in EI (Shapiro & Derrington, 2001) is a possible explanation for this disparity. It is puzzling to find greater disparity in enrollment than at referral. Further investigation of the underlying reasons for this disparity, and development of policies and practices that would increase access to EI services for uninsured children, are indicated.

## Immigrant Families

Study-specific investigation of length of U.S. residency indicated that recent immigration did not pose a barrier to referral. Existing EI records do not include information on immigration status; the lack of cross-source validation, as well as the unknown reliability of study-specific data, limit our confidence in the reported results. The need for data on this issue is more pressing given (a) national evidence indicating that children in immigrant families are less likely than other children to access health services (Benjamin, Wallace, Villa, & McCarthy, 2000) and (b) the present findings of enrollment disparity for children with no insurance, with which immigrant status is associated (Brown et al., 1999; Capps, Kenney, & Fix, 2003; U.S. Department of Commerce, Census Bureau, 2004c). The substantial effect size (2.83) of our comparison, however, suggests there has been some success in overcoming this potential disparity, which should be encouraging to other states that are experiencing high rates of immigration.

## Parents with Limited English Proficiency

Self-report affected data quality in both the Census and study data. EI providers who refer children may opt for the convenience and low cost of informal interpretation or reliance on limited communication and thus underestimate the actual need for interpreters. However, the fact that comparison with the combined Census categories

(spoke English "not at all" or "not well") indicated equitable referral gives us confidence that families with limited English proficiency were at no disadvantage in referral to EI. It appears that the professionals who referred these children were perceptive in recognizing the children's needs in spite of language differences and believed that the EI system could help these more challenging families.

Because the effect size of limited English proficiency on referral and enrollment depends on the Census categories to which study data are compared, qualitative study of the processes by which program staff decide whether a family needs an interpreter would be needed to establish which Census categories are the most appropriate standards for comparison.

Apparent equity in enrollment, however, depends on selection of the Census category for the comparison. If we compare our data with Census counts of people who reported that they spoke no English, we find no disparity in enrollment for children in families who need interpreters. If we instead use the joint Census categories of people who spoke English "not well" or "not at all," it appears that there is considerable disparity. This discrepancy held for analysis of records specifying need for interpreter and for analysis including unspecified records as indicators of no need, and it reaffirms the difficulty of comparing data from different interview protocols (in this case, study vs. Census protocols).

When families speak virtually no English, they and their providers are apparently consistent in recognizing the need for an interpreter. This consistency is reflected in the consistency of the results on referral and enrollment reported here. For families who speak some English, although not fluently, there may be cause for concern to the extent that the study data reflect real differences above and beyond any limitations in data comparability. Either real needs for interpreter services were not recognized, or there was enrollment disparity among referred children.

## Children in Military Families

Study-specific referral data indicated that children in military families were referred at a rate similar to that for the estimated population proportion. Enrollment data in the MIS indicated a substantial disparity, however, with 50% fewer enrollments than expected. These children may in fact receive some services through the military's Exceptional Family Member Program (EFMP), which is operated by the Department of Defense, although the program does not provide all of the services that EI offers. We did not have access to EFMP data for this evaluation, but in Hawai‘i, the Department of Defense encourages families with eligible children to enroll in EI, probably due in part to the resulting cost savings for the Department (A. Gamble, EFMP, personal communication, May 17, 1997).

Given our findings of equitable referral and disparity in enrollment, qualitative study of the processes following referral (see Figure 1) as they affect military families is indicated. Although data from EFMP records might decrease the observed discrepancy, these families would not receive all services available under EI. In addition, the lack of coordination between EFMP and EI, which resulted in our inability to access EFMP data, may mean there is duplication of services or that eligible children are "falling through the cracks."

## Homelessness

We originally intended to study homelessness but learned that none of our data sources could provide information on this potential barrier to referral and enrollment. Because program staff members record mailing addresses, including addresses of relatives, friends, or shelters, we could not determine homeless status from lack of a residence address. When asking additional study-specific questions at intake, program staff members specifically declined to ask about homelessness due to its stigma and the possibility that doing so would turn away needy families. It is regrettable that information on homelessness was not obtainable. Balancing the right of families to privacy with the need for data on which to base equity analyses and, perhaps, an enhanced service model would require an inclusive and thoughtful process, which does not seem imminent.

## Multiple Risks

We did not examine the impact of multiple risk factors on equity of referral and enrollment because we lacked appropriate, state-level population comparison data. Research has documented that the subpopulations we studied often overlap. For example, low income is associated with no insurance (Holahan et al., 2003; National Center for Health Statistics, 2002; U.S. Department of Commerce, Census Bureau, 2004a), immigrant status (Institute for Educational Leadership, 2003; U.S. Department of Commerce, Census Bureau, 2003b), and limited English proficiency (U.S. Department of Education, 2001). Approximately one quarter of clients receiving public nutritional assistance, which is available to families with children whose incomes are as much as 185% of the federal poverty level, were military clients (L. Chock, Hawai'i Department of Health, personal communication, June 20, 2002), a much higher proportion than the representation of military personnel and dependents in the state population (HIDBEDT, 2001). Immigrants also are likely to be uninsured (Benjamin et al., 2000; Brown et al., 1999) and speak English less than "very well" (U.S. Department of Commerce, Census Bureau, 2003a). It is possible that children with a single risk factor experience no disparity in accessing EI services, whereas children with additional risk factors are less equitably referred and enrolled. Perhaps activities undertaken to reduce disparity for families with a single risk factor may not be as helpful for those with additional disadvantages.

## Overrepresentation

An important theoretical question is whether reverse disparity (i.e., disparity favoring those with risk factors) represents inequitable treatment of populations without risk factors. A good example is the present finding that low-income children are referred more often than would be expected; this disparity may in fact reflect the established developmental risk associated with low income and demonstrate that children with or at risk for delays are referred without regard to income. On the other hand, families with more resources could be experiencing disparity. Many professionals serving young children in Hawai'i erroneously believe that a low income is an eligibility criterion that determines whether services are provided at no cost to families (Derrington & Shapiro, 2003), and they thus may not refer children from more affluent families. Reverse disparity also could represent referring professionals' biased perceptions, as is implied in reports of the overrepresentation of bilingual children in special education classes (Baca & Cervantes, 1989; Salend et al., 2002).

## CONCLUSIONS AND RECOMMENDATIONS

In general, this study provided reassuring evidence of equity in access to early intervention in Hawai'i. The distressing exceptions are disparities for uninsured children and those from military families. Guided by this research, Hawai'i's Department of Health implemented EI Child Find improvement efforts that have resulted in increased access, as demonstrated by dramatic increases in enrollment (National Early Childhood Technical Assistance Center, 2003). In addition, policymakers have forged better relationships and coordination between EI and the EFMP, although the effect of the improvements on data sharing is untested. Unrelated to this study, but serendipitously, pressures for accountability have resulted in a greater emphasis on data entry and management, which may lay the groundwork for better opportunities for research and future improvements.

Regrettably, no specific EI Child Find activities have as yet targeted uninsured children in Hawai'i. To the extent that professional misperceptions of insurance requirements are behind the disparity for uninsured children, outreach to referring professionals may offer a solution. A recent evidence-based outreach campaign con-

ducted with physicians in Hawai'i (Shapiro, Derrington, & Smith, 2003) has had promising results, although its effect on equity for demographic subpopulations has not been evaluated.

The results from our study are consistent with the current emphasis on evidence-based analysis in directing policy and programmatic decisions. However, repeated literature searches and professional inquiries have failed to identify any similarly comprehensive evaluations of EI Child Find equity in other states. Because individual states implement EI in very different ways, replication and extension of this study in other states would provide valuable information for state and national audiences.

A necessary first step for facilitating such studies is implementation of data systems that include more complete demographic information on all referred children. A few states (e.g., Florida, North Carolina, Rhode Island) have developed statewide EI databases, and many other states are in the process of doing so. A national study of the extent to which these databases support evaluation and accountability would assist the personnel of states that are contemplating such systems.

The processes following referral should be studied to (a) explain the different rates of referral compared to enrollment that have been reported for families with low incomes, with limited English proficiency, or who are in the military and (b) determine factors that may affect enrollment. Investigation of equity for children with multiple risk factors, who may be at increased risk for poor outcomes and disparity in access to services, is also warranted. A more challenging concern is how to study equity for homeless children without adversely affecting service access for this vulnerable group.

A recent national emphasis on disparities in access to health care (Kelley et al., 2004) is consistent with the importance our stakeholders attributed to equity in access to EI. The results of our study suggest that other states would benefit from investigation of equity in access to their EI services. Appropriate subpopulations may differ across states, but the issue of disparity in access must not remain unaddressed or reported only as proportions of referred or enrolled children belonging to a subpopulation without reference to the population proportion or another standard of comparison. We encourage other states to embark on similarly productive, evidence-based evaluations. ◆

## NOTES

1. This is the proper spelling of the word Hawai'i, which includes the punctuation known as an *okina,* signifying a glottal stop in pronunciation. It will be used throughout this article.
2. The Census Bureau's Historical Health Insurance Tables (U.S. Department of Commerce, 2004b) reported that in 2000, 7.1% of children in Hawai'i under age 18 had no insurance. We estimated the number of children under age 3 without insurance by applying this percentage to the number of all children under age 3 (HIDBEDT, 2000).
3. The U.S. Department of Commerce (2003a) reported the self-reported English-speaking ability of people in Hawai'i ages 18 and up. To derive data for an age group more likely to parent young children, we calculated the proportion of persons ages 18 and up who were ages 18 to 44 (HIDBEDT, 2000) and applied this proportion to the Census data on English-speaking ability.
4. The 2000 Census Population Estimates (HIDBEDT, 2001) do not provide figures for military dependents by age, but 1990 data were specifically obtained for this study from the Hawai'i Department of Business, Economic Development, and Tourism. Children referred to or enrolled in EI in 1997 would have been 3 years old to 5 years old in 2000. To estimate the number of children ages 3 to 5, we used 1990 Census data (HIDBEDT, 2000) to calculate the percentage of children in this age bracket among children under the age of 10 (29%). We then (a) calculated the number of children ages 3 to 5 who were military dependents in 1990 (0.29 × 25,506 = 7,397); (b) calculated the percentage of military dependents ages 3 to 5 out of all 1990 military dependents (7,397/ 63,215 = 0.12), and (c) applied this percentage to the number of all military dependents in 2000 (0.12 × 44,647 = 5,358).

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Yu, S. M., Nyman, R. M., Kogan, M. D., Huang, Z. J., & Schwalberg, R. H. (2004). Parent's language of interview and access to care for children with special health care need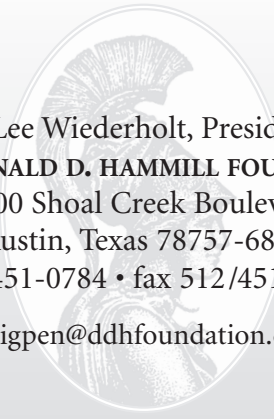s. *Ambulatory Pediatrics, 4*(2), 181–187.