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ABSTRACT

A random sample of 16 coordinators responsible for implementation of Part H of the Individuals with Disabilities Education Act were interviewed to determine if state data systems will be in a position to assist in monitoring service goals and in reaching populations typically underserved. The interviews assessed the availability of sociodemographic variables in states' Part H data systems and documented coordinators' perceptions of which population was most underserved in their state. It was found that: (1) accurate count of children served may still not be possible for 6 of 16 states; (2) 10 of the 16 states collect information on ethnicity of race; (3) data on family income were collected in 2 states; (4) none of the coordinators identified African Americans as underserved; (5) availability was a key barrier to rural populations, and both availability and accessibility were important barriers to ethnic minorities; and (6) in many cases, data were not collected for groups identified as most underserved. The study concludes that data systems should include the following sociodemographic information on their client population: county of residence, urban/rural/inner city residence, race/ethnicity, income, insurance coverage, and parental employment status. (JDD)

Carolina Institute for Child and Family Policy

PARITY OR EQUITY. CAN WE EVEN TELL?

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Executive Summary

Part H of the Individuals with Disabilities Education Act (IDEA) suggests that states should make a special effort to reach populations typically underserved. State data systems are an excellent mechanism for monitoring service goals. In order to determine if state systems will be in a position to serve in this manner, we interviewed a random sample of 16 Part H coordinators to assess the availability of sociodemographic variables in their Part H data system and to document their perception of which population was most underserved in their state.

Results

The major findings of the interviews are as follows:

1. An unduplicated count of children served may still not be possible for 6 of 16 states.
2. Ten of the 16 states collect information on ethnicity or race. However, of the 7 states that identified one or more ethnic minority as underserved, only 3 collected data on ethnicity.
3. Data on family income were collected in two states, but were not collected in a state that identified low income families as most underserved.
4. Of the 6 states that identified rural populations as most underserved, 2 included a variable that can reliably assess rural/urban residence.

5. Overall, availability was a key barrier to rural populations, and both availability and accessibility were important barriers to ethnic minorities.
6. None of the coordinators identified African-Americans as underserved.

Policy Recommendations

A very good way of identifying populations in need of services and of monitoring progress toward service goals, if for Part H data systems to include the following sociodemographic information on their client population: county of residence, urban/rural/inner city residence, race/ethnicity, income (preferably in terms of the family size), insurance coverage, and parental employment status. Because we recognize that it is intrusive to collect information on family income, in the report that follows we suggest ways of minimizing the intrusiveness and stress that families should have the right to withhold the information.

By having these data available, client characteristics can be compared to state demographics and to indicators of need. A brief illustration of how one aspect of coverage can be assessed is provided in the report. We stress the importance of identifying underserved populations accurately, because identification will dictate the strategies that are most appropriate for making services both available and accessible.

Introduction

It is implied in PL 99-457 (Sec. 678.6) (United States Department of Education, 1989) and stated more directly in PL 102-119 (Sec. 1471[a,5][1] and Sec. 1478[7])[2] (Individuals with Disabilities Education Act, 1991) that early intervention systems must make a special effort to reach populations that typically have been underserved. The general sociodemographic characteristics of the populations that are typically underserved are listed clearly in the legislation. Service systems should reach families who have low income, are ethnic or racial minorities, and live in inner cities or remote rural areas. Given the federal mandate, we sought answers to the following three questions. Are states in a position to identify progress towards serving unserved and underserved populations? What populations do states identify? Is the identified population in each state related to the demographics for that state? This document is a report of our findings.

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[1] The Congress finds that there is an urgent and substantial need- (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, minority, low income, inner city, and rural populations."

[2]States shall- (7) beginning in fiscal year 1992, provide satisfactory assurance that policies and practices have been adopted to ensure meaningful involvement of traditionally underserved groups, including minority, low-income, and rural families, in the planning and implementation of all the requirements of this part and to ensure that such families have access to culturally competent services within their local areas"

In serving traditionally underserved populations, it is not immediately clear from the legislation whether service systems should strive for parity or equity. And, we recognize that at this point, with many states serving less than 1% of the child population, the issue of service parity or equity may appear premature. However, systems are forged out of a vision and it is at this point, while many systems are still being created, that the vision must be clarified so that it may guide policy decisions.

Service parity means providing comparable amounts of services to all segments of a population. Thus, if 25% of a state's population has very low income, then under parity service goals, 25% of the client population would be from families with very low income (See MacRae & Wilde, 1979, for a discussion on vertical equity).

Service parity basically means that everyone gets an equal share. However, individuals do not all have equal needs and neither do populations. For numerous reasons (e.g., lack of adequate preventive health care, lower education, more hazardous living conditions) there are sub-populations whose needs are substantially greater than others (Egbuonu & Starfield, 1982; Miller, 1966; Zill & Schoenborn, 1990). These families should receive services according to their need.

If decision-makers in the Part H service delivery system think that it is important to serve families according to their need, then the goal becomes that of providing equitable services.

In such cases, families with very low income may very well make up 50% of the client population rather than the 25% that they represent demographically. We suggest that although the federal regulations do not specify equitable service goals, such is the intent of the law, and that indeed equitable services are the ethical course.

We propose that regardless of whether states set parity or equity service goals, a data system that includes the sociodemographic characteristics of the service population is an excellent way of identifying populations in need. Such as system facilitates assessment of progress towards service goals. Therefore, we randomly surveyed 16 states to determine if state data systems collected data on the sociodemographic characteristics of their service population. Because state awareness and definition of underserved populations could determine the type of data collected, we followed our initial interview with a second interview to determine which populations were considered underserved in the states that we sampled. Finally, we compared the state-identified underserved populations to state demographics to explore whether or not these might be associated. In other words, by examining state demographics could one predict which population is likely to be identified as underserved?

Method

Sample

Sixteen states were selected at random. A staff person who was not associated with the project picked 16 numbered slips of paper from a box. The numbers represented the 50 states in alphabetical order.

The sample was diverse. It included states throughout all geographical areas of the continental United States, states that are primarily rural, states with large metropolitan areas, states with minimal ethnic minorities and states with a large percentage of ethnic minorities. Our description of the sample is limited because we assured them confidentiality.

Procedure

In the first round of calls the first author talked with either the Part H coordinator or the staff person in charge of the Part H data system of all 16 states that had been selected. To determine if states collected sociodemographic information on their client population, she asked if the state-level database included information that could readily provide the following:

1. an unduplicated count of children served
2. the ethnic group or race of the children served
3. children's county of residence
4. whether a child resides in a rural or urban setting
5. families' income
6. whether or not families have private insurance
7. children's household composition

8. whether or not children's mothers were employed full time outside the home.

Approximately three weeks after the initial telephone interview, the first author again called the Part H coordinators and asked them to identify the population that was considered in each state as being unserved or underserved. Of the 16 states sampled, 15 state coordinators and one assistant responded to our inquiry. Resignation of one coordinator prevented collection of data from the last state. Specifically, the following four questions were asked:

1. What population is most unserved or underserved in your state?
2. Why is this population particularly underserved?
3. Is the early intervention system in your state doing or planning to do something special to reach that population?
4. What would you do to reach this population if you could do absolutely anything you wanted to do?

Results and Discussion

Sociodemographic Variables in State Data Systems

All states responded to our inquiry. Table 1 presents the results of the first telephone inquiry.

Table 1

Number and Percentage of States with Data Systems that Collect Sociodemographic Characteristics of the Population Served

	Number	%
Unduplicated count of children served	10*	63
County of residence	15	94
Rural or urban domicile	1	6
Ethnic group or race	10	63
Families' income	2	13
Private insurance	9	56
Household composition	4	25
Full-time maternal employment	1	6

Note. N = 16

* 5 additional states reported that they were either "trying" or "close" to being able to produce an unduplicated count of children.

Unduplicated count. As can be seen from the table, most of the states (n = 10) reported having a data system that allows them to report an unduplicated count of children. However, for a considerable number of states (n = 6) producing an unduplicated count is still a problem.

County of residence. All but one state reported coding county of residence. The one remaining state reported coding service area rather than county of residence. From the telephone interviews, it appeared to the first author that most respondents considered county of residence an adequate measure of rural/urban residence. Indeed, for states with counties that are either completely rural or completely urban, the county of residence may be sufficient. However, in addition to county of residence we suggest that states consider using a variable for "distance (or time) to (or from) nearest service." This variable could be particularly useful for states with populations in remote rural areas or with areas with very low population density. Another, quite possibly excellent alternative, because it pinpoints residence with more precision than does the county variable, was reported by one state. Its database uses zip codes instead of county of residence.

Race or ethnicity. Most (n = 10), but not all states reported coding children's race or ethnicity. One Part H coordinator volunteered that her[3] state did not include race in its database because its inclusion in the Part B database had been questioned severely by the federal government. Still another state is considering altering its data forms to include children's race or ethnicity.

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[3]To protect the identify of the few male respondents, all coordinators are referred to as "she" or "her."

Family income, insurance and household composition. Only two states reported coding family income. Nine states reported coding whether or not families had private insurance. Two states reported coding whether the children live with one parent, two parents, or a guardian. Another state reported collecting much more extensive data. Said state collects information on the number of adults and number of children in the household, maternal age and education.

Identification of the Populations Most Underserved

The 15 state Part H coordinators interviewed were approximately evenly split between those who identified rural populations (n = 6) and those who identified an ethnic minority (n = 7) as being most underserved. Interestingly, almost all the coordinators who identified rural populations as most underserved also mentioned that ethnic minorities were also underserved and almost all who identified ethnic minorities also stressed the needs of the rural populations. Often a large proportion of a state's ethnic minority resides in a rural area.

Although there was mention of transportation problems in cities and of the needs of African-American families, none of the coordinators specifically identified either families in inner cities or African-Americans as being most in need. One coordinator reported that there were no underserved populations in her state. She explained that her state was in the "Fifth Year" and that thereby the state had a system in place ready to serve all children in need.

Rural populations. Reasons for providing less than necessary services to rural populations included lack of personnel in rural areas, lack of good roads (mountain roads and/or roads impassable in winter), and long distances. Thus, overall, the Part H coordinators who identified rural populations as underserved, identified the problem as one of lack of available services. The coordinators reported that the following strategies were being planned or were being used to provide needed services:

1. allocating relatively more resources to areas with the least amount of services
2. on the job training by matching a professional with pediatric experience to a professional without pediatric experience
3. using a team of specialists to travel to where families live to provide assessment, planning, and review of implementation of the service plan through periodic visits, telecommunications, and/or videotapes.

When asked what their ideal solution was to reach the rural population, coordinators responded in terms of their needs to remove obstacles that they perceived as keeping them from reaching the rural population. Given that the major barrier to services in rural areas is that of availability, all coordinators in some way expressed the need for more personnel and more transportation. Even coordinators who did not identify the rural population as most underserved expressed the need for more

personnel. As one coordinator said, she needed "a fleet of cars and 17,000 O.T.s and P.T.s who would love to live in rural __(state)__." In addition, respondents also expressed needs that were not directly related to the number of professionals or to the availability of transportation. One coordinator expressed a desire to be able to channel much more of her energies to working more closely with community groups. Another wanted providers to truly have a family focus rather than the traditional child focus. A third wanted state legislation passed that would mandate services. She felt that without state legislation "people will never see Part H as an entitlement."

Ethnic minorities. Of the coordinators who identified ethnic minorities as most underserved, four identified Native Americans, one identified Latinos, another identified migrant farm workers -- most of whom are from ethnic minorities, and one identified upper income Anglos. In the latter coordinator's state, upper income Anglos constitute a minority. They enter the service system in disproportionately low numbers because private physicians refer them to other private providers.

The major barrier to services for Native Americans was that most lived in reservations that were typically far from the cities that had early childhood professionals. A second barrier was described as perceived or actual lack of responsiveness from the service providers to the needs of Native Americans. A third barrier was described as underidentification of children in the

reservations because parents tended to think that the child would "outgrow" the condition.

The coordinator who reported that Latinos were the population most underserved in her state identified lack of multicultural materials, and materials in Spanish as the major reason why Latinos were not receiving services according to their needs. Language differences and issues of trust were also identified as barriers for the migrant population.

Given the responses of the Part H coordinators, we suggest that whereas the major barrier to services for rural populations was lack of available services, the barrier to services for ethnic populations combine lack of services and their accessibility.

Current or planned strategies to reach ethnic populations included nominating a Native American to the ICC, increasing public awareness within the reservation, coordinating closely with the Migrant Head Start Program, and developing bilingual public awareness materials. Ideal solutions for reaching ethnic minorities included: providing sensitivity training to personnel, hiring personnel from the same cultural background as the target population, and hiring a liaison Native American whose job would be to ensure that early intervention services were culturally appropriate.

Families with very low income. One coordinator reported that families with very low income, particularly those who cannot read, constituted the population most removed from the service

system. She did not specify a level of income that constitutes a problem, but identified five ethnic groups in her state that tend to have low levels of education and/or very low income. She reported that services often do not accommodate to the needs of these families. Services may be rendered only from 8 o'clock in the morning to 5 o'clock in the afternoon, families may have to take two or three buses to reach services, and enrollment forms may be particularly complex for parents with low literacy skills.

To overcome the traditional barriers to services, this state has funded minority service grants that have developed appropriate materials or approaches for the target populations. The state also tries to have a demographically diverse group of families in a family information network that serves as a resource to new or potential clients.

In terms of ideal strategies to reach families with very low income, this coordinator suggested that she needed vehicles, particularly vans, to be able to take the services to the families. If given the resources, she would also use drop-in child care for siblings and she would seek additional expertise on cultural diversity. She asked, "What do we have to do to be (culturally) competent?"

The Underserved Population versus the Sociodemographic Characteristics Collected in the Part H Data System

Will states be able to monitor progress towards serving populations that have been underserved? Of the 6 states that identified the rural population as most underserved, 1 included a variable containing families' zip codes and another included an urban/rural variable. All other states included the county of residence in their database. As mentioned above, county of residence may be a sufficiently adequate variable for some but not all states. Thus, we suggest that 2 of the 6 states have a data system that lends itself to monitoring progress.

Of the 7 states that identified an ethnic minority (including upper income Anglos and migrant farm workers) as underserved, 3 had a variable on race or ethnicity in their database. The coordinator who identified very low income families as most underserved does not have an income variable in her database. However, the coordinator who reported that no one group was underserved in her state had a database with all of the variables that we inquired about except for one on rural/urban residence.

Overall, 5 of the 14 states that identified an underserved population have data systems that will allow them to assess progress towards service goals, should they so desire.

Identified Underserved Population versus State Demographics

Are the underserved populations as identified by Part H coordinators related to the states' demographic characteristics?

There was a trend to identify Native Americans as underserved if the state had a population of Native Americans. States that had minimal or no Native American populations tended to identify rural families as underserved. However, there was no definitive pattern of identification. The identified population was not necessarily the largest minority population in each state.

African-Americans are the largest ethnic minority in the country, and 3 of the states in the sample were among the top 10 states in African-American populations. Interestingly, none of the coordinators identified this population as underserved. Unfortunately, given the scope of this study we cannot speak to the validity of coordinators' identifications. Two of the three coordinators from these states identified rural families and the third identified Native Americans as the population most underserved. In 1 of the 3 states with a high percentage of African-American population, approximately half of the African-American population was in the state's largest city and the percentage of African-American population in that city was approximately 33 percentage points higher than in cities with fewer than 250,000 inhabitants and in rural areas. In the other 2 states, the percentage of the population that was Africa-American was roughly comparable across urban and rural areas.

Implications

There are three main reasons why states may not be collecting the sociodemographic data that will help them monitor

service goals to populations that they have identified as underserved. In some cases the "Part H staff" consists of only a coordinator and a secretary. There are so many demands on coordinators' time that they may not have had an opportunity to plan ahead to monitoring service goals. We recognize that coordinators must deal with numerous issues that may compete for their available time. Nonetheless, we suggest that inclusion of basic demographic information may be a worthwhile investment in spite of the time, effort, and good will from local providers necessary to make needed changes. The inclusion of sociodemographic data will allow for later analysis of the extensiveness of the coverage of the Part H system.

Second, very legitimate concerns of confidentiality and right to privacy may curtail the data that are collected. To maximize confidentiality, data systems can use a unique identifier for each child. The identifier can consist of the child's gender, birth date, and the first three letters of the child's first and last name.

Lastly, the reason that specific data are not collected, nor service goals monitored may be because knowing that a segment of the population is underserved presents still one more set of problems that need to be addressed. Even though such may be the case, the focus of analysis on the coverage of services need not be negative. Measurement of service provision can be positive by focusing on progress. Moreover, by documenting service needs, states gain authority to request funds. Part H programs may

improve their chances to increase their funding base, which in turn could be used to increase services and/or alleviate the staff's workload.

Policy Recommendations

Data Needs

Whether parity or equity service goals are set, if decision-makers at service systems wish to monitor the extent to which their service goals are met an excellent way is to use their data systems. In such cases, the data systems must be able to provide unduplicated counts of children receiving services **and** the family characteristics of those children. State level data on children who receive services should provide their county of residence, whether the family lives in an urban, rural, or inner city setting[4], the ethnic group of the family, a four or five level income classification variable, family's insurance coverage, and whether or not the child's parent(s) are employed full time.

Despite the fact that data on family income can be a sensitive issue, we suggest that states give serious consideration to collecting this information. It is important to collect family income data because assessment of service delivery goals are most relevant for families who do not have the option of seeking private care. Research on health services utilization indicates that families who are most underserved are not those

[4]Geographically large states might want to include a variable indicating the amount of time it takes the family to drive to the nearest city of a specified size.

below the poverty line, who are eligible for Medicaid, but those immediately above the Medicaid eligibility criteria who may not have the resources to cover the cost of services (Butler, Winger, Singer, & Wenger, 1985). Affluent families may opt for services in the private sector, and as long as they have equal access to the public service system, they need not be considered underserved if they choose private providers.

Because some families may object to divulging family income, families must have the right to withhold that information. Also, they must be assured confidentiality, and the purpose of collecting sensitive information must be explained. Moreover, the data must be collected in a manner that minimizes intrusiveness. Family income is meaningful in terms of the poverty line, the exact dollar amount of which differs according to family size. Thus, family income may be collected in terms of four or five broad categories that represent 100%, 150%, 200%, and 250% of the poverty line. For example, for a family of four the 1991 poverty level was $13,254. In 1992 parents in a family of four could be presented 5 categories: below $13,254; $13,254 to $19,881; $19,881 to $26,508; $26,508 to $33,135; and above $33,135, and asked to select the category that best describes their total family income for the previous year.

The list of sociodemographic variables suggested above represents a minimum. Each state needs to include the variables that will best capture the characteristics of its population. For example, whereas one state may include a race variable with

only two levels (white and black) another state may wish to include an ethnicity variable with four or five levels (white majority, African-American, Latino, Native American, Asian-American).

With the basic family characteristics described above, a service system can monitor parity service goals. The characteristics of the client population can be compared to the known state demographics. Are as many children who live in remote rural areas receiving services as those who live in urban areas? Is the proportion of client children on public insurance comparable to the size of the population that is eligible for public insurance? Are the children of two working parents being served in proportion to the number of two-working-parent families in the state?

How might service data be used to monitor service goals?

For the purpose of illustration, we analyzed one small aspect of assessment of services. We examined the geographical distribution of services in one state. We divided the number of children (birth-to-three) served in one year in each of the state's geographical service areas by the number of birth-to-three-year-old children in each service area and multiplied times 1,000 to derive the ratio of children served per 1,000 children in each service area. In the state we examined, the service ratio ranged from 24.33 to 1.13 per thousand children. Obviously, there was considerable disparity among service areas in this one state.

Lack of parity among service areas may be due to many factors. A legitimate reason for lack of parity is differing need for services in various service areas. For example, families with young children with cerebral palsy may tend to move to a particular city that has a well-known and highly regarded program. In such a case, that service area would show a disproportionately large number of children receiving services. Another service area may include a military installation that provides services to a large number of the young children in need and so, that service area may show relatively few children served. A third area, with very high per capita income may have a relatively small clientele because a large number of families may rely on private providers.

There may be legitimate reasons why areas differ in the number or type of children served. The person who evaluates results needs to be knowledgeable about the state characteristics and services. As with all other evaluations, analysis can be more of an art than a science, but having the kind of information that we have suggested, allows examination of the reasons why service areas may differ. For the state that we illustrated, we conclude that although there may be legitimate reasons for diversity, the range between 24 children served per 1,000 in one area and 1 child served per 1,000 in another area is a fairly clear indication that some geographical areas were being underserved.

Thorough assessment of coverage. The example above is a small part of what could be done to monitor progress towards service goals. To do a complete evaluation of service coverage, many other aspects of service delivery should be considered. The results of these can then be put together to arrive at a "complete picture" of the service system. For example, large states with small populations in remote rural areas would do well to examine the number of children served per children per 100 square miles, to determine if the children in remote rural areas have access comparable to that of children in the cities.

Other potentially important sociodemographic indicators that could be used for comparison to client characteristics are per capita income, the number of minority children served per 1,000 minority children, and the number of children from two-working-parent families. Moreover, given that families in the upper income levels may opt for services in the private sector, service goals may best be assessed in terms of the state population of families under 200% and 250% of the poverty line.

Monitoring Equity Goals Requires More than Service Data

Assessing progress towards equity goals is much more difficult than assessing progress towards parity, because equity is dependent on need, and need is very difficult to determine given that the data generally available are service data. In other words, service data do not identify the population that needs services, but is unserved or underserved.

There are no good measures of need, but there are basically two indicators of need that are not dependent on services: birth outcomes, and number of students requiring special services at school.

In particular, states that include in their birth records a "user-friendly" method (e.g., checklist for recording birth defects) will have a fairly good indicator of the prevalence of various birth outcomes of this example among sub-populations. Two relevant outcomes are the prevalence of low birthweight and the prevalence of congenital defects. An obvious drawback to this source of data is that not all conditions of interest to early intervention systems are observable at birth.

A second indicator of need is the number of children who receive special services at school entry or shortly thereafter. Almost all children attend public schools, and all school children with special needs are entitled to services. Thus, the number of school children receiving services is another indicator of actual need. If the school system also collects the types of sociodemographic data that we have suggested, then early intervention systems can estimate need by sub-groups. The two drawbacks to this source of data are: (a) The eligibility criteria for early intervention services and for school services are not always the same; (b) School systems differ among themselves in their criteria for providing special services. Nonetheless, the characteristics of the population of children who receive special education in elementary school can provide

Part H systems with important indicators of need for early intervention.

Other Ways of Assessing Coverage

We have focused on using the data system to assess service goals because we think that once the data collection system has been set up, this method provides a very efficient avenue. However, all states may not be able to undertake this option. States that have substantial local control of service programs may have difficulty coordinating the multiple sub-systems. Similarly, states that already have a well-established system in place may have difficulty modifying it.

A second option to a comprehensive data system is to conduct a one-time or occasional study to assess unmet needs. The study could be of a cross-section of the client population. Alternately it could focus on a specific geographical area or population. For example, services to Native American groups who reside on reservations could be monitored with greatest scrutiny to document child find efforts and meaningful participation of parents and the community.

Accurate Identification of the Underserved Populations

We wish to stress the importance of identifying underserved populations accurately. Accurate identification of the population that is underserved and a clear understanding of the factors that contribute to inadequate service provision are necessary to improve the delivery of services. For example, if Native Americans are underserved in a given state and most of the

Native American population is also rural, what is the factor that determines their being underserved? Is it distance to services or is it cultural differences? The answer will determine in part the appropriate strategy to take in order to provide services. The first step once underserved populations are identified, is to make services available. However, once services are available, the issues of accessibility and cultural appropriateness must be considered with care.

To summarize, we have suggested that:

1. Data systems can be used to identify underserved populations, set service goals and monitor progress towards those goals.
2. To operate in this fashion, data systems should collect sociodemographic information on their client population.
3. Service goals can be assessed by comparing the characteristics of the client population to state demographic characteristics and to indicators of need.
4. The goal of Part H systems should be to provide services equitably.

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