Farmworkers and disability: results of a national survey

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This paper describes the findings of a national study of farmworkers with disabilities. BPA conducted an in-person survey with a purposive sample of 201 adult farmworkers with disabilities and 66 disabled children in farmworker families in six states. Results show that adult and child farmworkers experienced a wide range of disabilities. Adults most commonly experienced back problems and other musculoskeletal problems. Children most commonly experienced developmental delays. However, both groups experienced a wide range of physical, sensory and cognitive disabilities, including chronic health problems. The survey also asked about service recognition and use. While farmworkers recognized and utilized a wide range of farmworker-specific and mainstream services, they used very few disability-related services, such as vocational rehabilitation and special education. Understanding more about farmworkers' views of disability would help disability service agencies improve outreach to this population.

Keywords: Farmworkers, service utilization, vocational rehabilitation

1. Introduction

Very little research exists about farmworkers and disabilities, and little is known about the kinds of disabilities that they experience, their views of disability, and their experiences with the disability service system. Farmworkers are a difficult population to study, due to their transiency, tendency to live in nontraditional households, and minority status and limited English proficiency. When research is done on the health status of farmworkers, it uniformly finds that they experience worse health status than the population as a whole, and have difficulty with access to health care [5, 6,10]. These assessments of acute health care needs usually do not address disability.

It would be logical to assume that farmworkers experience a higher incidence of disability as well as many acute health conditions, for a number of reasons. Many chronic health conditions that farmworkers disproportionately suffer from, such as diabetes and hypertension, can result in disabling conditions, such as visual impairments, loss of limbs, and heart disease. In addition, the rigors of farmwork – the hard physical labor, poor living conditions, potential for accidents, and pesticide exposure – point to a higher likelihood of disability, and indeed farmwork is generally recognized to be the second most dangerous occupation after mining [12]. The lifestyle of migrating farmworkers has its own set of conditions that put farmworkers at higher risk for substance abuse and mental health problems, as well as a higher probability of automobile accidents and less access to physical and mental health care [9].

For all that we suspect that farmworkers have a high incidence of disability, however, there is very little evidence that this is so, and for most people the term "disabled farmworker" is an oxymoron. After all, the typical vision of farmworkers includes young and vigorous men who can endure long hours of backbreaking labor, and the stereotype of disability usually limits itself to people who use wheelchairs or canes. In both cases, of course, the reality is much more complex. Many farmworkers, in fact, work with significant disabling conditions, including many disabilities that are not visible. Many farmworkers do not identify themselves as disabled, and consider themselves farmworkers even after disability has forced them to stop doing farmwork. Farmworkers may avoid applying for services because they are not citizens, or because of language and transportation barriers, or simply because they know they will encounter prejudice. If farmworkers are a largely invisible population to most of society, then farmworkers with disabilities are the most invisible among them.

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While they may be eligible for more services because they are more likely to be U.S. citizens, disabled farmworker children share the invisibility of their families. Farmworker parents often have high educational goals for their children, which they hope will lead them to a life beyond farm labor. However, parents with low educational achievement often have difficulty in maneuvering their children through the mainstream school system, let alone special education or other services designed to help children with disabilities. Farmworker children with no special needs are sometimes incorrectly placed in special education because they lack facility with English. For students with special needs, the barriers to service are formidable. Schools often lack adequate bilingual staff and translators, assessments are sometimes done in English instead of Spanish (causing inaccurate results because of language barriers) and school staff may put less effort in helping migratory families because they know that the children will leave after a few months. Some farmworker children with severe disabilities are truly invisible, because their families keep them away from the public eye, both for fear and shame.

This study sought to shed some light on the issue of disability among farmworkers and their children. Conducted by Berkeley Planning Associates (BPA) and the National Center for Farmworker Health (NCFH) under a grant from the National Institute on Disability and Rehabilitation Research,[1] the study collected data from a non-random sample of disabled adult farmworkers and disabled children in farmworker families. This in-person survey asked about disability and health status, as well as experiences with the mainstream and disability-specific service systems. While we could not establish the incidence of disability in the population (since a good sampling frame for farmworkers does not exist), the data presented below give an overview of the kinds of disabilities that farmworkers experience, and the range of their service needs. We supplement the survey data with information gathered during site visits to the areas where the surveys took place. Finally, we offer some thoughts about the implications of our findings for future research and practice.

[1] Berkeley Planning Associates is an employee-owned firm with more than 25 years of public policy research and consulting experience. The National Center for Farmworker Health, Inc., is a non-profit resource and technical assistance center serving Migrant Health Centers and the general public with information about farmworker health. For information about either the organizations or the grant, please contact Marlene Strong at Berkeley Planning Associates.

2. Who are farmworkers, and why do they need vocational rehabilitation services?

Farmworkers are the people who plant, nurture, and harvest the foods we eat every day. They are hired by growers (i.e., farmers who own the land) for wages to perform certain tasks, often through the intermediary of a farm labor contractor. No one definition of "farmworker" exists, however. Usually the term refers to those who work in fruits, nuts, and vegetables, but it can also include workers in nurseries, field crops (such as cash grains), tree farms, and livestock production. Often programs refer to "migrant and seasonal farmworkers"; these terms simply attempt to distinguish between those who travel from their homes to work and those who work during the growing season while living in one place. Very few farmworkers can work year-round.

Most people who identify themselves as farmworkers have either grown up doing that kind of work or come from a farmworker family. For many, being a farmworker is more than just an occupational classification; it is an identity and a lifestyle. Long-term farmworkers are only part of the population; for many others, farmwork is something that they do when they first immigrate to this country, and then they move on to other jobs. (Individuals with higher levels of education are especially likely to say that they do not intend to stay in farmwork.) Therefore, the farmworker population consists of both long-term workers, and a group that continually turns over as new immigrants replace workers with better prospects.

The data show the farmworker population in this country increasingly is made up of Latino males, many of whom are recent immigrants with low levels of education and limited English language proficiency [8]. However, in some parts of the country native Anglos (in the Midwest and Plains states) and African-Americans (in the Southeast) still do a substantial proportion of farmwork. Other pockets of non-Latino farmworkers include Haitians in Florida, Southeast Asians in California, and Native Americans in the Dakotas. Contrary to the common perception that all farmworkers are illegal immigrants, the majority (63%) in fact are citizens or have work authorization.

2.1. A population at risk of disability

As mentioned above, farmwork is the second most dangerous occupation, after mining. Farmworkers suffer from occupational injuries that can be disabling, such as: falls, loss of limbs, heat stress, dehydra-

tion, dermatitis, eye problems, and pesticide poisoning. Farmworkers seldom have paid sick leave, and economic pressures make them reluctant to miss work to have occupational injuries or illnesses treated, unless the condition is so severe that it prevents them from working.

Few rules govern child labor in farmwork, and children as young as age ten can legally do farmwork. Thus, farmworker children may be exposed to the same risks of occupational injuries as adults. Even when they do not work in the fields, children may play there while their parents work, leaving them vulnerable to pesticide poisoning and accidents from farm machinery.

Studies of farmworker health have shown that this population's health status resembles that of workers in underdeveloped nations [5]. Many of the chronic and severe health conditions common among farmworkers are disabling, such as: diabetes, hypertension, chronic urinary tract infections, parasitic infections, respiratory infections and tuberculosis, arthritis, anemia, and musculoskeletal injuries due to constant physical labor. Limited access to oral health care severely compromises dental health.

Farmworker children are thought to suffer from higher rates of birth defects (due to maternal and paternal exposure to pesticides) than the general population, although limitations in research data have made it difficult to support this conclusion [12]. In addition, farmworker children suffer from high rates of asthma and chronic otitis media, which leads to hearing losses. The mainstream service systems may or may not identify these children as needing special education and, eventually, Vocational Rehabilitation transition plans.

Farmworkers often live in conditions that contribute to and exacerbate their health problems. Housing, especially for those who migrate, is poor to nonexistent. Farmworker housing often lacks inside running water, electricity, heat, or laundry facilities. Many farmworker camps have poor water quality and inadequate wastewater disposal, insect and rodent infestations, and are overcrowded. Conditions in the fields are often quite dangerous, with a lack of toilet and hand washing facilities, little access to safe drinking water, and unsafe use of pesticides.

For all these reasons, farmworkers are at risk of disability. Nonetheless, research on this topic is limited. Cortés [4] published the last known research about farmworkers and disability nearly a quarter century ago, and his sample was limited to one state (Texas). A recent doctoral candidate [11] interviewed only a very small sample (15 people) in Wisconsin. Our survey did not substantiate the myth that farmworkers go back to their home countries (e.g., Mexico) when they become too disabled to work. We included a question about whether the disabled respondent knew of other farmworkers with disabilities who had returned to their home countries. Only 7% of respondents indicated that they knew anyone fitting that description. Farmworkers with disabilities are a neglected and invisible population, but they are here to stay, and they deserve to have access to services.

Because it is impossible to draw a national random sample of farmworkers in order to arrive at incidence and prevalence estimates of disabilities, we designed our study to seek out farmworkers with disabilities in a representative sample of states and find out as much as possible about their disabilities and service use and needs. Based on this information, we developed dissemination materials and recommendations for future research. Below, we describe our methods and our results.

3. Methodology

The study used two methods of data collection: (1) an in-person survey of approximately 200 farmworkers with disabilities, and 60 disabled children of farmworker families, in six states; and (2) case study visits to the same states, including interviews with a variety of service providers and advocates involved with farmworkers. We chose a purposive sample of states: three homebase and three upstream, with one pair in each of the three generally recognized migrant streams (western, Midwestern, and eastern). We selected states based on the number of settled out seasonal workers and the size of the migrating population. The six states were: California, Washington, Texas, Colorado, Florida, and North Carolina; in each state, one or two communities were chosen for interviews.

BPA and NCFH selected local bilingual, bicultural individuals, recommended by staff at the migrant health center in each community, to administer the survey. The study team conducted an in-person training for the interviewers in Denver, Colorado in January 1996.

In order to supplement the quantitative data collected about individuals in the survey, the study design included qualitative community-level case studies. These case studies explored issues of service access, coordination and barriers for disabled farmworkers, both adults and children. Site visits allowed us to search for examples of best practices as well as to identify ar-

eas for system improvement. Research staff from BPA conducted the case study visits, spending two to three days at each location. During these visits, BPA researchers conducted open-ended interviews with staff from the community health center, special education and migrant education programs, job training programs for farmworkers (i.e., JTPA Section 402 programs), vocational rehabilitation, and local farmworker advocates.

3.1. Survey design

The project had an advisory board consisting of researchers specializing in disability and farmworkers, farmworker advocates, and a disabled farmworker. This panel of experts provided significant input into our final project design and survey instrument. In addition, members of this panel contributed to some of the project's dissemination materials.

BPA developed the survey instrument for use with adult respondents, and then adapted it for child respondents. Staff at NCFH translated both versions of the survey into Spanish. A migrant health center staff member pretested the survey in Texas. Interviewers administered the surveys in person on a paper-based instrument that took about 45 minutes to complete. The project gave respondents a $10 money order for participating.

The survey sample was not random. The study developed a snowball sample in each site, identifying respondents through referrals from health center staff, word of mouth, community canvassing, and referrals from survey respondents. Surveys were completed during March through September 1996.

The instrument included an initial screening section, which limited the sample to individuals with disabilities who had conducted farmwork within the previous five years, were between the ages of 18 and 55 (birth to 17 for children) and lived within the local area. Bilingual staff at NCFH verified data by telephone on a random sample of completed surveys. BPA staff cleaned, postcoded, entered, and analyzed the resulting data. BPA staff presented preliminary findings at each of the three regional migrant stream forums held in late 1996 and 1997.

Because the adult and child surveys were not identical, we analyzed most data from these two groups independently. However, in our analysis of service utilization we grouped adult and child respondents from the same family together. We did this for several reasons. In some cases, we interviewed several individuals (both adults and children) from the same family. Moreover, when we asked about service use, we asked respondents to answer for themselves or anyone in their family. We collapsed responses from multiple respondents who belonged to the same family, so that service utilization would not be over reported.

In defining disability, we chose to use a functional definition of disability instead of a categorical one. Asking respondents whether their condition caused them *to change the amount or type of farmwork* they did allowed us to understand how the impairment or health condition affected their lives. Two people with the same condition might not be equally disabled by it. Moreover, a functional definition helps separate cultural perceptions and biases about a particular condition from the effects of a certain set of physical conditions on an individual's life. Finally, a functional definition allowed our results to be compatible with data from national surveys such as the National Health Interview Survey.

The adult and child surveys were quite similar, though not identical. Each survey had four sections. The first section asked about personal characteristics. The second section asked about the individuals' health and disability. This section included a self-rating of individuals' physical, emotional and overall health, and their expectation for how their overall health would be in one year. The second section also asked about limitations in activities of daily living, as well as usage of and need for adaptive aids.

The third section asked about service use. This section included a table listing 19 specific services, plus a generic category for writing in "other" services. The interviewer asked if the respondent had heard of each service, and if within the last two years, respondents or anyone in their families had applied for and/or received the service listed. If the respondents (or any family member) had applied for the service, we asked the status of the application. If respondents (or any family member) had received the service, we asked about their satisfaction or dissatisfaction with the service. If the respondent was dissatisfied with a particular service, we asked the reason for dissatisfaction. In the adult survey, this section also included a few specific questions about vocational rehabilitation services. The final section asked if the respondent knew of any other farmworkers with disabilities who could participate in the survey.

Although the format of the child instrument was quite similar to that of the adult instrument, we tailored the instrument to children in two ways. First, the services

listed in section three on service utilization included several services specific to children with disabilities (such as special education, maternal and child health follow-up, and special services for disabled children). Second, instead of asking about vocational rehabilitation, the child instrument asked about use of and satisfaction with special education.

When interviewing adults, we instructed interviewers to ask survey questions of the disabled adult directly, instead of through another family member. For the children's survey, we instructed interviewers to ask questions of the child's parent or guardian, unless the child was old enough to answer the questions thoroughly and thoughtfully (presumably no younger than a teenager). For all children, we asked that the parent or guardian remain present during the interview. All child interviews required the consent of the parent or guardian.

4. Characteristics of the survey sample

Table 1 summarizes the characteristics of our respondents. Our survey sample was uniformly Latino. We had not set out to limit the sample in this way, nor had we instructed interviewers to seek only farmworkers of Hispanic descent. The sample reflects the majority of the farmworker population, which is predominantly Latino [8]. Among adult respondents, our sample includes a two-to-one ratio of men to women (63% versus 37%), reflecting the greater proportion of males in farmwork [8]. Among children, our sample was more evenly split between males and females (54% versus 46%). More than three-fourths of the adult respondents (76%) were married or living with their partner. More than half of the respondents from both groups spoke English poorly or not at all (adults: 57%, children 58%). However, the child sample included a significant proportion of very young children who had not yet begun to attend school (where they will learn English). Regardless of their facility with English, the vast majority of all respondents listed Spanish as their primary language (adults: 91%; children: 86%).

Although three-fourths of the adult respondents were born in Mexico (73%), three-fourths of the child respondents were born in the U.S. (74%). A few respondents in both groups were born elsewhere, most often in Central America (adults: 4%; children: 2%). While two-thirds of the adult respondents were non-U.S. citizens (66%), only a quarter of the child respondents were non-U.S. citizens (26%). Seventy-nine percent of the adult respondents had authorization to work in the U.S., which is higher than the overall rate among farmworkers (63%) found by the National Agricultural Workers Survey [8].

Table 1
Characteristics of respondents

	Adults ($n = 201$)	Children ($n = 66$)
Latino	100%	100%
Female	37%	46%
Male	63%	54%
Average age	39 years	8 years
Currently doing farmwork	61%	NA
Average age began doing farmwork	18 years	NA
Born in US	23%	74%
Born in Mexico	73%	24%
Born elsewhere	4%	2%
Highest grade completed	6th	NA
Primary language is Spanish	91%	86%
Speaks English poorly or not at all	57%	58%
Household income under $15,000/year	84%	92%
Non-U.S. citizen	66%	26%
Had work authorization	79%	NA

The majority of the sample lived in poverty, with most respondents living in households with income less than $15,000 a year. Among adults, 84% live at this income level, which on average, supports 4.4 people. The child sample is even poorer: 92% live at this income level, which on average, supports 5.4 people. On average, most adults had only a sixth-grade education (usually completed in Mexico).

Most of the adults (61%) were still doing farmwork at the time of the interview. (Too few children did farmwork to analyze in any meaningful way.) On average, the adults had started doing farmwork at age 18 years, and those who had stopped did so at age 39 years. The survey asked adults about the kinds of farmwork they performed or used to perform. The vast majority (83%) did the most physically demanding farmwork tasks, such as hoeing, thinning or transplanting, harvesting/picking, and digging ditches. The remaining respondents performed less physically demanding tasks, such as irrigating, operating machinery, applying pesticides, or field packing, sorting, or grading. About a third of those doing less demanding tasks said they had switched to these tasks because they were no longer physically able to do other types of farmwork. The survey asked respondents about their exposure to pesticides during the past five years. The majority (62%) had worked in a field recently treated with pesticides, herbicides, or insecticides, and 19% had applied these chemicals.

4.1. Disabilities among adults

We used a screening survey to find adult farmworkers who said they had changed the amount or type of farmwork they had done due to a disability or chronic health condition. As shown in Table 2, 89% of the adults said that their disability caused a reduction in the amount of farmwork they did, and 71% said that it caused a change in the type of farmwork (e.g., no longer migrating). Although we did not set out to find people who had been disabled by farmwork, a majority (65%) of the adults attributed their disabilities to the farmwork they had done. The average age of onset of the primary disability was 32 years (range = birth to age 55), and the vast majority of the respondents (86%) expected their disability to continue for at least one year.

To determine the kinds of disabilities experienced by survey respondents, we asked an open-ended question and then post-coded their responses into categories. If respondents reported multiple disabling conditions, the survey asked which one caused the greatest limitations, which we considered to be their primary disability. We did not seek clinical confirmation of the health conditions and disabilities respondents reported. We suspect that this method actually under-reports disabilities, because farmworkers may suffer from many undiagnosed conditions (e.g., hearing loss, vision impairments, mental retardation), and respondents are less likely to report some non-visible disabling conditions without prompting, such as psychiatric disabilities, AIDS, and substance abuse disorders. In fact, very few respondents reported any of these stigmatized non-visible conditions.

Table 2
Health and disability

	Adults ($n = 201$)	Children ($n = 66$)
Age of onset of primary disability	32 years	2.2 years
Expects disability to continue for one year	86%	77%
Believes the disability is a result of farmwork	65%	NA
Disability caused reduction in amount of farmwork	89%	NA
Disability caused change in type of farmwork	71%	NA
Self-rated physical health		
Poor	47%	26%
Fair	45%	47%
Good	9%	26%
Very Good	0%	2%
Self-rated mental health		
Poor	25%	26%
Fair	39%	47%
Good	30%	27%
Very Good	6%	0%
Self-rated overall health		
Poor	28%	26%
Fair	60%	61%
Good	11%	14%
Very Good	2%	0%

Table 3 shows the primary disabilities reported by adult respondents. Nearly a quarter of the adult sample reported that a back condition was their primary disability. The second-largest primary disability category was other musculoskeletal conditions, such as injuries to joints (knees or elbows), carpal tunnel problems, or paralysis of limbs. Therefore, more than a third of the respondents (35.2%) reported conditions that very well could have resulted from the hard, repetitive physical labor of farmwork.

Back conditions are the main cause of work limitation for the US population as a whole as well, with 16.4% of adults aged 18–69 reporting this as their primary disability [7]. Heart disease is another condition that has a high incidence in the overall population, with 12.1% of adults aged 18–69 reporting this as their main cause of work limitation. In comparison, only 2.9% of the farmworkers in our sample reported heart disease as their primary disability. This disparity may be because the farmworkers we interviewed were younger on average than the population included in the national databases; the average age of the adults in our survey was 39 years, and we limited our sample to those aged 55 and younger.

Other disabilities reported by the adult farmworkers ran the gamut from diabetes to neurological problems

Table 3
Disability conditions – adults

	Percent reporting condition as primary disability	Percent reporting this condition
Back condition	22.5%	29.9%
Other musculoskeletal	12.7	27.9
Other physical	9.3	22.9
Diabetes	8.5	15.9
Visual impairment	8.5	18.4
Psychological disorder	6.0	11.9
Arthritis	5.0	10.0
Respiratory disorder	5.0	7.0
Neurological disorder	4.5	10.5
Kidney disorder	3.5	9.5
Hypertension	3.5	13.9
Chronic pain	3.5	7.5
Heart disease	3.0	4.0
Cognitive	3.0	1.0
Hearing impairment	1.5	4.0
Chronic health condition	0.5	1.5

(including head injuries and epilepsy) to psychological disorders (such as anxiety and depressive disorders) to sensory disorders such as vision and hearing impairments. Since this was not a random sample, we cannot generalize from this sample to the farmworker population as a whole. While many people assume that disabilities among farmworkers will be primarily musculoskeletal conditions, our survey shows that farmworkers experience a wide range of disabilities, just as the general population does. Some are chronic health conditions, such as diabetes, hypertension, or kidney disease, and others are congenital conditions or those acquired through farmwork or accidents.

Most of the adults (63%) reported more than one disabling condition. The second column of Table 3 shows the proportion of the adult sample with that condition, whether or not it was their primary disability. Our data show that 71% of our sample reported physical disabilities such as back problems, other musculoskeletal conditions, other physical conditions such as limb paralysis or amputation, or arthritis. When we consider secondary conditions, the proportion reporting diabetes, hypertension, respiratory disorders, and other chronic health problems rises to 41%, and more than 18% report visual impairments (which can be a result of diabetes).

Although people with disabilities can be in good health, these disabled respondents reported being in poor health. The survey asked respondents to self-rate their physical health, mental health, and overall health (see Table 2). The vast majority of the adults (92%) rated their physical health as only "poor" or "fair". Although respondents rated their mental health better, almost two-thirds (64%) still rated it as poor or fair. Nearly nine out of ten respondents (88%) rated their overall health as only poor or fair. When asked about their expectation of their overall health in one year, a similar proportion (86%) responded with poor or fair. Interestingly, the distribution between poor and fair varies between the two questions. When asked about their current overall health, 28% of respondents rated it as poor, 60% rated it as fair, and 11% rated it as good. But when asked about their prediction of their overall health in one year, 36% report it as poor and 50% report it as fair and 13% report it as good. Thus, many respondents expect their overall health to deteriorate in the coming year. The fact that many of the farmworkers' disabilities were chronic health conditions could have contributed to their poor health status. The health conditions were treated, however: only 12% of adults had not seen a doctor about their disabling condition, and 65% were currently taking medication.[2] Despite this high proportion, respondents repeatedly cited the need for specialist care, more medications, and assistance with paying for medications.

Table 4
Functional limitations – amount of assistance needed in the following areas

	Adults		Children Age 6+	
Bathing, grooming, and other	26%	A Little	28%	A Little
self-care	5%	A Lot	33%	A Lot
Communicating with and	20%	A Little	19%	A Little
understanding others	9%	A Lot	39%	A Lot
Acquiring new skills, learning	35%	A Little	31%	A Little
new things	13%	A Lot	34%	A Lot
Moving from room to room	19%	A Little	40%	A Little
	3%	A Lot	17%	A Lot
Managing one's life, making	20%	A Little	26%	A Little
decisions	6%	A Lot	51%	A Lot
Living on one's own*	28%	A Little	26%	A Little
	14%	A Lot	57%	A Lot
Maintaining a source of	35%	A Little	24%	A Little
income*	40%	A Lot	61%	A Lot

*On the child survey, parents were asked to project how much assistance their children would need in the future with these items.

Respondents reported using a number of assistive devices, such as canes, wheelchairs, braces, and walkers, but often more respondents needed the device (or needed a new one) than were currently using one. Glasses were the most commonly used assistive device, with 40% of respondents using them, and 18% needing them. Of those already using glasses, 75% reported needing new ones. A few respondents also reported needing assistance with sensory disorders, saying that they wanted to learn ASL (9%) or Braille (9%), or needed a hearing aid (8%).

In order to get information about the severity of the disabilities experienced by farmworkers, we asked about the amount of assistance needed in seven functional areas (Table 4). Not surprisingly, maintaining a source of income was the area where respondents were most likely to report that they needed a little (35%) or a lot (40%) of assistance. Adult farmworkers also reported needing assistance with living on one's own (42% reported needing assistance) and with acquiring new skills (48%). Fewer respondents reported needing help with mobility (22%), self-care (31%), communication (29%), and decision-making (26%).

4.2. Disabilities among children

Among children, disabilities were more likely to be the result of congenital conditions; the average age of

[2]This result is most likely related to the fact that we recruited many of our respondents through the migrant health centers.

onset of disability was 2.2 years, and 56% were disabled at birth. As with adults, the children's survey asked parents an open-ended question about their child's disability and we post-coded their responses. As shown in Table 5, children had a wide range of primary disabilities. The most prevalent were developmental disabilities or delays caused by conditions such as mental retardation or cerebral palsy. The second most common were a variety of physical conditions, such as paralysis, deformities of the limbs, cancer, cleft palate, and anemia. Neurological disorders were mostly epilepsy, and respiratory disorders were mostly asthma. There is some speculation in the farmworker community whether congenital anomalies, epilepsy, and other childhood disabilities may be the result of high levels of pesticide exposure among pregnant farmworker women. (Our study could not test this hypothesis.)

Some farmworker children also had sensory disabilities such as hearing and visual impairments. Often hearing loss is due to chronic ear infections, which can be untreated if the family has limited access to a migrant or community health center. As seen in the second column of Table 5, these disabilities were secondary conditions for a number of children: our data show that nearly one-quarter (23%) had hearing impairments or communication problems, and 8% had visual impairments. Nearly half of the children (47%) had multiple disabling conditions.

As with the adults, this nonrandom sample does not yield results that can be generalized to the population of farmworker children. However, it shows that children in farmworker families experience a wide range of disabilities that require medical and developmental services for treatment. Children also used a variety of assistive aids and medications, and many reported needing new ones.

Table 5
Disability conditions – children

	Percent reporting condition as primary disability	Percent reporting this condition
Developmental delays	24.2%	28.8%
Other physical	16.7	27.3
Respiratory disorder	10.6	15.2
Musculoskeletal	10.6	16.7
Neurological disorder	9.1	13.6
Hearing impairment	7.6	13.6
Heart disorder	6.1	9.1
Endocrine disorder	4.5	–
Visual impairment	3.0	7.6
Psychological disorder	3.0	7.6
Kidney disorder	1.5	3.0
Arthritis	1.5	1.5
Communication	1.5	12.1
Chronic health condition	–	7.6

The survey asked about their children's current functional limitations, as well as their future capacity to live on their own and maintain a source of income.[3] Parents judged that their children needed more assistance than the adults reported across all the functional areas (see Table 4). Explanations for this finding include: 1) parents currently do things for their children and cannot imagine that they will be able to learn independent living skills, or 2) the children in the sample were more severely disabled than the adults, or 3) the types of disabilities the children experienced (e.g., developmental delays) have different effects than those the adults experienced. As seen in Table 4, the majority of parents reported that their children need assistance in all areas. In all but one area (mobility), more parents thought that their children needed "a lot" of assistance than "a little".

The survey also asked parents to assess their disabled children's physical and mental health status (Table 2). Parents were more likely to rate their children as having "good" or "very good" physical health (28%, compared to 9% of the disabled adults). However, parents rated their mental health lower, with only 27% being rated "good" and none rated "very good" (compared to 36% of adults). Parents may project their own fears about living with a disability on their children, and judge them to be anxious or depressed about this. Responses may have been different if we asked the children directly (or if the adult survey had asked a family member to rate respondents' health status instead of the disabled adults themselves). The distribution of responses for overall health are very similar for both adults and children, but this masks the underlying differences between the groups in the views of physical and mental health that respondents reported.

4.3. Use of services

Studies of farmworkers have shown that farmworkers and their families are less likely to use the services for which they were eligible because of barriers such as language, transportation and cultural differences (see, e.g. [3,6,8,9]). To learn more about these barriers, we asked respondents to list reasons for dissatisfaction with any of the services they used. We also hypothesized that farmworkers may underutilize services because they do

[3] These data are for children ages six and older.

not know that certain services exist. To test this hypothesis, we asked each respondent if s/he had ever heard of each of the 19 services listed in Table 6. We could then compare the frequency of service recognition to service utilization. As discussed above, service recognition was tested on an individual basis, while service utilization was calculated by family. Also, most child surveys were completed by parents on behalf of their disabled children. Thus, the survey tested the parent's recognition of services, not that of the children. We refer to these respondents as "parent respondents" in the discussion below.

Our survey respondents probably had higher service utilization than the farmworker population as a whole, because we identified the vast majority of respondents through the migrant and community health system, a system that often serves as an advocate and information resource for this population. Only 5% of our sample had not used any of the 19 services we listed, and another 8% had only used one service. Almost three-fourths had used between two and six of the 19 services. Fifteen percent had used more than six services. Yet, although this was a highly connected farmworker population, service recognition and use remained quite low for disability-related services.

The services most widely used were direct food and medical benefits for impoverished families with children. Disability-related services were less recognized and far less utilized. Not surprisingly, the four most recognized services were also the four most utilized ones: migrant/community health centers, food stamps, Medicaid, and WIC. However, although the vast majority of respondents were impoverished and would qualify for these services, far more respondents recognized these four services than used them. Ninety percent of adult respondents and 98% of parent respondents had heard of migrant health centers, but only 70% had used their services. Similarly, 89% of adults and 94% of parent respondents had heard of food stamps, but only 58% had received them.

Beyond these basic food and medical services, the gap between service recognition and utilization only grows wider when considering services designed for people with disabilities. Although 72% of adults and 76% of parent respondents had heard of disability payments (such as SSI, SSDI and state disability payments), only 27% of families received these payments. About half of adult and parent respondents had heard of developmental disabilities services, but only 5% had used them, which is particularly troubling given the large number of children in the sample with developmental delays. Although 60% of adult respondents had heard of Workers' Compensation – and 65% felt that their disability was work-related – only 8% used this service.

In spite of the fact that 87% of the adult respondents said that they would be interested in help with learning the skills needed to do work other than farmwork, training and education services were among the least utilized. Over half of adult and parent respondents had heard of ESL and GED services, but only 13% had used ESL services and only 10% had used GED services. Moreover, only 6% of respondents had used JTPA services.

The adult survey also asked about vocational rehabilitation. One-third of adult respondents had heard of vocational rehabilitation, but only 1% of respondents had used these services, the lowest recognition and utilization rate of any adult service. Other studies have shown that farmworkers face many barriers in utilizing vocational rehabilitation services including language and transportation barriers, attitudinal barriers by providers, a desire to return to farmwork instead of retraining for a different profession, and migration patterns that make it difficult to complete the long assessment process associated with these services [3].

Our site visits revealed similar barriers to vocational rehabilitation services, particularly in states that did not have special funding targeting the farmworker population (Section 304 grants). States with special farmworker vocational rehabilitation grants had made significant progress in recruiting and serving this population. In those sites, the vocational rehabilitation agency had either hired bilingual/bicultural staff, or assigned existing staff to work closely with local health center staff, often accompanying them on mobile health units that went directly to labor camps or the fields. This teaming helped overcome language barriers and general distrust, with health center staff who were familiar to local farmworkers serving as liaisons.

The child survey asked specifically about special education. Seventy-one percent of parent respondents had heard of special education, but only 7% had children who were enrolled in special education classes. This is partly explained by the fact that only half of our sample had children who were of school age (age six and older), and not all youth with disabilities need special education services. However, not all the sample children who were of school age were attending school, a fact that suggests that those most disabled, and perhaps most in need of special education, were not even attending school. In addition, all states have

Table 6
Service recognition and receipt

Services	Adult Survey Recognition ($n = 201$)	Child Survey Recognition ($n = 66$)	Family Utilization ($n = 229$)
Cash			
AFDC	70%	70%	23%
Disability Payments (SSI, SSDI, or State)	72%	76%	27%
Unemployment Insurance	79%	62%	24%
Workers' Compensation	60%	39%	8%
Food			
Food Stamps	89%	94%	58%
WIC	81%	95%	44%
Food Bank	64%	65%	20%
Health			
Migrant/Community Health Center	90%	98%	70%
Medicaid	86%	95%	58%
Mental Health/Counseling	56%	41%	8%
Crippled Child Services (CCS)	NA	41%	2%
Maternal and Child Health	NA	66%	4%
Alcohol/Drug Treatment	72%	70%	3%
Education			
ESL	64%	58%	13%
GED	58%	52%	10%
JTPA	36%	38%	6%
Special Education	NA	71%	7%
Other			
Low Income Housing	66%	61%	15%
Mental Retardation/Developmental Disabilities Services	50%	52%	5%
Vocational Rehabilitation	33%	27%	1%
Veterans Benefits	52%	36%	1%
Legal Services	66%	56%	11%

now implemented early intervention services (serving children aged 0–3) that should have reached even the youngest children in our sample.

In many places, Migrant Head Start (which, like all Head Start programs, has a mandate to fill 10% of its slots with children with disabilities) serves young disabled children in farmworker families and facilitates their transition to the special education system. During our site visits, we tried to learn more about the relationship between migrant education and special education, as well as the linkages between Migrant Head Start and the school system. There was great variety across study sites in the level of coordination among these three entities. In some sites, migrant education did not serve any students with disabilities, and staff were hardly aware that some farmworker children had disabilities. In other sites, migrant education staff saw themselves as advocates for all children of migrant families, and referred students to special education staff as needed while continuing to serve them through migrant education as well. Staff at these sites also ensured that migrant children were not incorrectly referred to special education based on limited English proficiency skills.

Migrant Head Start staff often worked very closely with special education staff to ensure that students with special needs were not lost in transition. These individuals served as translators and taught parents how to act as advocates for their children. In one case, the agency running Migrant Health Start served both homebase and upstream states, and would facilitate the transfer of a child's Individual Education Plan (IEP) to the upstream state. Thus, for the farmworker children lucky enough to be eligible for Migrant Head Start and able to use this service, their disability needs were addressed. Many other disabled farmworker children are not served by the special education system.

4.4. Reasons for dissatisfaction with services

To learn more about the reasons for dissatisfaction with services, we asked respondents whether they were dissatisfied with the services they used and why. We provided a list of ten reasons for dissatisfaction as well as two open-ended "other" categories. Our findings were unusual because we only asked about dissatisfaction with services that the respondents were already

using (and not barriers to getting services they were not receiving). For example, several barriers that other studies of farmworkers commonly report were not cited by anyone in our sample, namely transportation and services not being available when farmworkers could access them. More than one in every ten respondents (11%) however, used the open-ended category to report that they were dissatisfied because services were "not enough", a reason we had not included in our precoded list.

As Table 7 shows, the reasons respondents were dissatisfied with services fell in two broad categories: either services were insufficient and difficult to access, or respondents experienced cultural barriers when accessing the services. Reasons under the former group included services being too far away or too expensive, having to wait a long time before receiving the service, or simply, services not being sufficient to meet the family's needs. Respondents also were dissatisfied because services were culturally inaccessible, saying that service providers do not "understand my problems", "like me", or "speak my language".

5. Conclusions and implications for future research and practice

Our study found that adult farmworkers and children in farmworker families experience a wide range of disabilities, ranging from musculoskeletal problems to sensory disorders and chronic health conditions, just like the general population. These disabilities cause functional limitations for farmworkers in their work and life outside of work.

While our sample of farmworkers was fairly well connected to farmworker-related and mainstream social services, such as migrant health services, Medicaid, Food Stamps, and WIC, very few were using disability-related services, such as vocational rehabilitation or special education. Farmworkers who are not using mainstream social services are even less likely to find out about appropriate disability-related services. The reasons for dissatisfaction with services cited by our respondents can also be barriers to accessing services at all: for example, cultural barriers such as language barriers, and access issues such as being too far away or too expensive.

Table 7
Families' reasons for dissatisfaction with services they were receiving

Services Insufficient/Difficult to Access	Percent of Respondents ($n = 267$)
Services not enough	11%
Too much of a wait for services	10%
Do not have the services I need	6%
Services too expensive	3%
Services too far	1%
Cultural Barriers to Services	
Do not understand my problems	10%
Do not like me	3%
Do not speak my language	3%

For this very poor population, taking time away from work to use services is difficult. Further, many services have legal requirements that recipients be U.S. citizens, which is a barrier for those who have only work authorization. Also, farmworkers may not have access to services that other workers take for granted: for instance, farmworkers are not fully covered by Workers' Compensation in 36 states, and their wages are often unreported by growers or farm labor contractors to the Social Security system, limiting their access to Social Security Disability Insurance (SSDI). Without such sources of income support, the possibility of using JTPA or vocational rehabilitation services for retraining is very difficult, especially for heads of households.

Farmworker children may face barriers to services because their families are poor and disenfranchised. Their parents may not have the language skills to negotiate special education programs, and even if language is not a barrier, cannot take the time away from work to advocate for their children or attend IEP meetings. Applying for Supplemental Security Income (SSI) for their children requires understanding a complicated set of eligibility criteria and forms. Thus, even if children are more likely to be eligible for services because they are US citizens, the barriers faced by their families are still very real.

Part of the reason for farmworkers' lack of knowledge about disability-related services may be that the service providers that they are most likely to have contact with, namely migrant health center staff, do not understand the disability service system. During our site visits we often found that health center staff did not have the time or understanding to guide patients through the often confusing set of eligibility criteria for disability-related services. In an era of funding cutbacks and managed care, health center staff often find that they barely have time to deliver adequate treatment for acute conditions, let alone provide case management services to help farmworkers with disability services. BPA and NCFH developed a dissemination product specifically to address the information needs of health center staff with respect to disability-related services [1].

Conversely, disability service providers may have little understanding about the unique needs of farmworkers, who tend to be invisible and often cannot advocate effectively for services to meet their needs. The barriers to entry that farmworkers face in accessing vocational rehabilitation services, for instance, have been well documented [3]. BPA also developed a dissemination product aimed at vocational rehabilitation counselors, to help them better serve farmworkers [2]. This booklet would also be useful for other mainstream service providers who need basic knowledge about farmworkers.

However, providing informational resources about disability to farmworker service providers and resources about farmworkers to disability service providers may not address the whole issue of farmworkers' access to disability services, simply because it does not take into account the attitudes of farmworkers themselves about disability. Because the vast majority of farmworkers are members of ethnic minority cultures, it may be that low levels of disability service utilization are grounded in the understanding that farmworkers have about disability.

Our study could not shed much light on this topic, because our survey consisted primarily of closed-ended questions, and we spent most of the time during site visits interviewing service providers. However, anecdotal evidence suggests (and our experience corroborates) that many farmworkers carry beliefs about health and disability that are different from the majority culture. Since many farmworkers are Latino, we can look to the Hispanic culture for clues to their belief system. The National Advisory Council on Migrant Health described it this way:

> *Hispanic culture views illness differently from Anglo culture. While the mainstream culture regards illness as an impersonal and blameless event – the result of germs or fate – the traditional Hispanic culture regards illness and health as being connected to harmony between the natural and the supernatural. Thus, an individual's illness reflects on his or her relationship with the community and with God, and a system of folk medicine has developed to restore harmony to the body and the spirit when these relationships somehow become unbalanced. ([9], p. 22)*

The very notion of "disability" may not be a clear one for many farmworkers. For instance, many farmworkers may not understand that one can have a disability and still work. One researcher interviewed 15 farmworkers in Wisconsin who had chronic health conditions that resulted in (often severe) functional limitations [11]. However, none of her respondents considered themselves disabled, because they continued to work (although some had reduced the amount or type of work they did). To them, being disabled meant not being able to work at all, and being totally dependent on others. Our survey findings support these findings. Sixty-one percent of the adults we surveyed continued to do farmwork even though they had conditions generally accepted as disabling.

A holistic view of health and a black-white view of disability may make it difficult for farmworkers to accept the "disabled" label. The notion that some process can "rehabilitate" them is often a foreign concept, and one that is difficult to translate into Spanish, the dominant language of farmworkers. The independent living movement and disability rights culture are virtually unknown.

On site visits, we picked up a flavor of fatalism about disability, derived from a mixture of Roman Catholicism, extreme poverty, and generalized oppression by a country that values the fruits and vegetables farmworkers pick but not their presence, which is seen as different, foreign, and transient. Such fatalism may be adaptive, given the poor prospects that disabled adult farmworkers have for obtaining needed rehabilitation services and other retraining services.

As long as farmworkers' attitudes are opaque to the disability service system, conducting effective outreach to this population will be difficult. Further research that explores these attitudes could have a great impact on the ability of farmworker families to access disability-related services.

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