Planning for the Economic and Career Impact of a Sickle Cell Anemia Program

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ALTHOUGH many health problems achieve publicity and priority through emotional appeals on behalf of those who are afflicted with the disorder, few health problems are invested with symbolic, civic, or ethnic content. Poliomyelitis and its association with President Roosevelt is perhaps the best example of a health issue achieving this civic symbolism and subsequent grassroots support through the vehicle of the March of Dimes. Recently the problem of sickle cell anemia has become invested with the symbolic ethnic identity of the black community. The relatively widespread nature of the disorder naturally focuses the community's concern. The prevalence rate of sickle cell anemia in black infants in this country is 1 in 400. Approximately 1 in 10 blacks are heterozygous carriers of the trait for hemoglobin S, and therefore information about their sickle cell status should be available, *if desired,* to serve as a basis for informed decisions about childbearing. The fact that the molecular biology of the disease is well elaborated and yet no cure or even fully successful treatment is available increases community concern. Finally, the probable survival advantage held by the trait carrier in malarial regions (*1*), balanced polymorphism, is often mentioned in public media presentations on sickle cell anemia, and it is presented in terms of the tenacity, strength, and will to live of the black race. This turns defect into asset and makes the resolution of the former concerns seem less difficult.

Although some black professionals have been concerned about placing too much emphasis on sickle cell anemia when clearly many other health problems disproportionately affect persons in the poverty group, the symbolic content of the disease, plus its discrete, limited implications, make it an issue easy to champion. Recent articles, however, have documented the relative unawareness of the black population about sickle cell anemia. A survey in Richmond, Va. (*2*), disclosed that only 30 percent of those questioned had ever heard of this disease. In a group of military recruits screened for sickle cell disorders (*3*), only 5 of 75 identified as having traits had any awareness of this problem in themselves or in other family members.

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Funding for Sickle Cell Anemia

The low public awareness of sickle cell anemia has been coupled with a low priority for funding from government sources and from foundations. Scott (*4*) has compared the relative incidence of sickle cell anemia to other rare diseases such as cystic fibrosis and muscular dystrophy and matched these with dollar figures raised by voluntary agencies. Although the incidence of sickle cell anemia and cystic fibrosis is about equal, 20 times as much money was raised for cystic fibrosis. The incidence of muscular dystrophy is only two-thirds that of sickle cell anemia, but 80 times as much money was raised for muscular dystrophy.

Scott (*5*) has called for a reordering of priorities and adequate support for research and treatment for sickle cell disorder. Clearly, government support and increased private support for sickle cell anemia will be forthcoming. Current Federal allocations are in the range of $10 million, and bills with much higher dollar figures are currently before the Congress. Community expectations on the potential funding are often unrealistically elevated. Groups look toward this as a source of support for many activities directly and indirectly related to the management of sickle cell anemia. Groups seeking funding for sickle cell screening have looked at it as a vehicle to introduce high school students to science. Others see it as a way to engage black people in the health care delivery system. Almost all see it as a source of training and jobs.

Economic Impact of Sickle Cell Program

The dimensions of the potential job impact are not clear. Also the dollar economic impact is unclear, but presumably large. An example of this conception of potential large dollar input appeared in a recent issue of the Black Panther newspaper. The headline was "The Sickle Cell 'Game,' Phoney Foundations Try to Sabotage Black Panther Party's Sickle Cell Program." The article expresses the following sentiment: "The overwhelming majority of these sudden sickle cell foundations do not have as their goal the wiping out of sickle cell anemia. To the contrary, they would rather the disease remain, killing off black people, so that they can continue to perpetuate their organization, and make the big profits that the 'Sickle Cell Game' is now pulling in" (*6*). Clearly this kind of rhetoric operates on several levels. The primary concern here is the assumption of big "profits" inherent in potential sickle cell programs.

Rational, comprehensive health planning must deal with the issue of profits. The success and impact of a health program will, in large part, be conditioned by the realistic expectations of those involved. Ignoring such considerations can only lead to program dissatisfaction, program underutilization, and ultimately, program failure. From the positive side, it is imperative to incorporate rough job and economic estimates into initial plans to achieve anything other than short-term dollar benefits, especially if meaningful career development is a secondary goal.

Table 1. Distribution of black population (N = 605,336) in six California counties, by age group

County	Age group (years)		
	Under 15	15–24	25–44
Los Angeles	84,013	132,830	202,041
Alameda	15,412	31,066	39,054
San Francisco	9,475	17,990	25,254
Contra Costa	4,405	8,091	9,679
San Mateo	2,822	4,870	7,161
Santa Clara	2,167	3,704	5,329
Total	118,294	198,551	288,518

Table 2. Approximate unemployment of black youth aged 15–24 in six California counties

County	Male		Female	
	Total	Unemployed	Total	Unemployed
Los Angeles	61,519	11,073	71,311	17,114
Alameda	15,147	2,726	15,919	3,820
San Francisco	8,593	1,534	9,397	2,254
Contra Costa	3,855	693	4,236	1,017
San Mateo	2,385	429	2,485	596
Santa Clara	1,836	330	1,868	448
Total	93,335	16,785	105,216	25,249

NOTE: Grand total unemployed male-female is approximately 42,034.

Considerations in California

In 1970 the total population of California was 19.9 million, of which 1.4 million persons (7 percent) were black. Seventy-nine percent of the black population live in six counties (table 1), and the remainder are widely scattered throughout the other 52 counties in the State. The six counties are in the San Francisco Bay area and Los Angeles. Obviously a program directed at sickle cell anemia will be focused on this geographic area.

To estimate the impact of a sickle cell anemia program on jobs, knowledge of program content is critical. Buetler and associates (*7*) have outlined some hazards of indiscriminate screening, and they suggest that two appropriate target groups for testing are young children and women of childbearing age. Women found to have the disease should be given genetic counseling.

A sickle cell screening and counseling program will have a variety of component parts. Some components will be professional and some nonprofessional but will be potentially leading, with training, to a professional level. The training will include counseling, outreach, and some aspects of testing. In the absence of existing community genetic counselors for mass screening programs, it is difficult to estimate the number of man-hours needed to insure adequate training of community counselors, as well as to actually provide counseling for screenees with the disease. Based on some funding proposals that we have analyzed, a reasonable estimate is 1 man-hour per patient screened, which includes training and actual service. In the six counties under consideration, this estimate means that about 600,000 man-hours, or about 300 man-years, would be needed to accomplish the job. To screen and counsel 79 percent of the black population in California, therefore, approximately 300 community residents might be employed in a sickle cell program.

Of course, black professionals would be in-

cluded in the sickle cell program, and the total cost of the project might be large. However, black professionals not employed in the program presumably would have other employment. Thus, the net gain to the local community is about 300 new short-term jobs. A continuing screening-counseling program would require fewer personnel to cover newborns and newcomers to the community.

Young people would be a prime target for employment in a sickle cell program. An estimated 40,000 black youths in the target area are currently unemployed. The 1970 national percentages of unemployment among black youth aged 16–24, were as follows:

Age	*Male*	*Female*
16–17	27.8	36.9
18–19	23.1	32.9
20–24	12.6	15.0

Immediate implementation of a sickle cell program with job opportunities aimed at these youths would alter their unemployment rate by only 0.7 percent. Thus there would be little impact on the unemployment situation, and recognition of this fact could lead to addressing the question of black unemployment realistically and to the development of meaningful health careers relating to mass screening for genetic diseases.

Program development for sickle cell anemia may be a model for development of general genetic screening programs. Attention to ethical and social issues is essential. The guidelines published by a research group on the ethical, social, and legal issues in genetic counseling point to a direction to take. Concerning counseling, they state that "well-trained genetic counselors should be readily available to provide adequate assistance for persons identified" (*8*).

Programs have not yet been established to prepare counselors for mass genetic screening programs. However, with the widespread interest in genetic diseases and the importance of aggregate genetic disease in a population's health status, many genetic screening health programs of similar types will likely be developed. A good example is the Tay-Sachs Program. Therefore, the role of the genetic counselor is not connected with only sickle cell anemia, and employment opportunities will occur in other screening programs.

In California the Bureau of Maternal and Child Health has been working with the Center for New Health Careers in the State Department of Public Health to formulate guidelines for the development of meaningful careers at all levels in genetic screening health programs. Obviously, health professionals must aim at insuring (*a*) that the training is conducted in a manner that will bring about its recognition by educators, (*b*) that it is related to, and builds on, previous formal education, and (*c*) that it becomes a vehicle for facilitating future formal training. Also, training should capitalize on the life experience of the trainee and develop that person's empathy and understanding.

Because the counseling effort required in mass genetic screening cannot be accomplished by doctoral level persons, a graduate program leading to a master's degree in genetic advising has opened on the campus of the University of California at Berkeley. Six students entered this program in the fall of 1973. Clearly such a program is not directly relevant to the question of entry level positions in a mass screening program. However, it does present a new career ladder for employees participating in mass screening at the entry level.

Conclusion

Planning for new health programs must consider community expectations, develop projections of economic impact that will add realism to these expectations, and look toward long-term benefits from career development.

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