

"LONG TERM PROGRAMMING FOR THE
DEVELOPMENTALLY DISABLED IN KOSCIUSKO COUNTY"



Study and Recommendations by
Donald Pinnick
Member of Kosciusko Leadership Academy
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One of the greatest thrills in life is experienced in the first moments of parenthood. "Is it a boy or girl?" The mother, father, nurses and doctor are all jubilant because it is a joyous occasion. It happens every minute across the country and is generally accepted as not an unhappy occasion. The new father and mother plan and look forward to the next few years at home; seeing their little one start to crawl, coo, walk, talk, etc. Each of us gets excited about the various milestones of development and just marvel at how bright our child is. We enroll them in school and we're off. The worries of parenting are multiple and unique.

Let's think for a moment about what would happen if the child was not normal? There would not be feelings of euphoria. This is something that we as parents don't want to even think about, but what if it would happen to you? Two to four percent of babies born today are born with defects which will prohibit a normal life. That percentage may be increasing because technology is saving more and more babies who are born with physical problems. There are many different feelings at this time, but no one is thinking about how great an impact a handicapped individual will have on the family. The divorce rate for families of handicapped children is one of the highest for any category.

Historically, families of severely handicapped individuals had two options: institutionalization of the child or the decision to provide for their youngster themselves. The public schools have just in the last few years accepted these students in the schools. In 1973 their inclusion in public education was mandated in Indiana. Before that parents had to provide educational programming on their own. It should also be pointed out that the schools only have an obligation to provide educational programming from 5 to 18 years of age.

Handicapped individuals are found in all segments of society and their problems are experienced throughout the world. Kosciusko County is not an exception, and it must do its best to effectively provide for these individuals and their

family.

As stated, most people are not really aware of the hardships that are placed upon a family when a severely disabled child becomes part of the family. I think we can all sympathize with each family, but we really don't feel any responsibility to help them deal with their problems. We, as a society or individuals, rarely feel any obligation to help.

Just recently a very large controversy arose in the southern part of Indiana when a family of a newborn severely handicapped child let the child die through starvation. The press presented the moral issue here as well as the productivity point of view, i.e., the individual would never be a contributing member of society. Yet it was the family of this child that would have been responsible for its future, not us.

Personally and professionally I have had many experiences with parents of handicapped children. One of the sadest and most difficult tasks for individuals like myself is to help parents deal with their feelings and needs. Many of these people never experience a normal life. They can't have normal vacations or evenings out of the house because no one will babysit. Some of them never get sleep at night because their child stays awake at night. Their houses are child proofed, i.e., locks for everything. Friends and relatives don't want to visit. But what is really sad is that this is not an eighteen year obligation. This is forever and then some. Parents have to plan for their handicapped individuals after their death. Do relatives take them? Are siblings forced to take them into their home? Institutionalization is next to impossible, so the answer is that the family must fend for itself.

The question is, who are we to condemn parents of these individuals for some of their actions? Another question raised is, should a family be punished because they unfortunately have a handicapped child? I have already given examples of some physical and personal problems of parenting handicapped students.

Another problem is the financial burden placed upon these families. It is the American dream to get ahead financially and do those nice things we all dream about doing some day. Most parents of these individuals will never have that opportunity to fulfill those dreams because of possible medical expenses and the expense for schooling or long term placement of a handicapped child.

Society has made large strides in meeting the needs of these individuals, but has it really assumed all of its responsibilities? Should parents of handicapped children assume the full burden of having a handicapped child or should society? None of us ask to have a handicapped child born to us but it could just as easily and unexpectedly happen to anyone.

My feeling is that society must shoulder this obligation because a handicapped individual can unexpectedly become part of any family, at birth or later through accidents, illness, etc. It is a reality that these individuals, the handicapped, do have rights and some are very capable of contributing to society.

Nearly thirty years ago some parents in Kosciusko County established the first programming for their severely handicapped sons and daughters. In 1954 a group of parents formulated the Kosciusko County Council for the Retarded, Inc., and they started classes with one teacher. The program bounced around the community to various locations, including the old Armory and the Lutheran Church in 1955. The organization had continual funding problems, and therefore, continually sought aid from individuals and the community. The first budgets were less than \$2,000, and in 1958 they had to borrow the \$2,000 so they could have a program.

In 1963, the program moved to a two story building on High Street and stayed there until 1965. In 1965, the organization received a \$10,000 county tax levy to start a workshop, and in March 1966 the present property was purchased. Three years later in 1969 a building drive started which culminated with the present facility in 1974. The Kosciusko County Council for the Retarded purchased and

ran a residential property for twelve clients for semi-independent living in 1973. One can see that there were great strides made during the sixties and seventies in Kosciusko County for the mentally handicapped.

In the 1980's the trend is reversing itself. During the past year the Cardinal Center has closed its residential program, therefore eliminating that as an option for the developmental disabled residents of Kosciusko County. This Spring the Cardinal Center had to eliminate most of its services for over a two month period. They are reopening its doors for limited services in May. During the 1981 year the Cardinal Center offered services to 160 clients; when they reopen they will offer services to 80 or fewer clients. The cost to operate the program rose to over \$1,182,000, but as in every business funds have been cut back.

Due to funding cutbacks priorities at the Cardinal Center have had to change. The Cardinal Center had offered the following programs over the years: workskills and training program (to train individuals for competitive employment); Work Evaluation Program (makes recommendations regarding vocational training); Work Adjustment Training Program (job placement service for the developmentally disabled); Shape and Preschool Program (serves children with developmental disabilities age 0 to 5); Adult Basic Education Program (no longer sponsored by Cardinal); Nutrition Program (the Cardinal Center's site provided meals to senior citizens); Residential Services; Adult Day Activity (programming for the lower functioning individuals). The Nutrition Program and the Residential Service are no longer provided while the Adult Daily Activity will be severely reduced.

The mission of the Cardinal Center, Inc. is to provide information and referral, evaluation, habilitation, vocational and/or support services, in the least restrictive environment available and in an effective and efficient manner, to Kosciusko County and surrounding area residents who have developmental edu-

cational employment, therapeutic, and/or independent living needs. The mission is a very credible one which most people support, but financially the Cardinal Center cannot provide this total programming to meet the community's or its clients' needs. Everyone is aware of the financial cutbacks at the federal and state levels which greatly burdened the Cardinal budget causing reduction in force and programming.

If one believes that it is society's responsibility to provide care of the developmentally disabled and that the residents of a community should share in the costs for this care, then the citizens of Kosciusko County should evaluate what they are doing. During the 1981 budget year the total budget for Cardinal was \$1,182,000. Of those dollars \$25,000 was donated by United Way and another \$20,000 by the County government. The residents of Kosciusko County support approximately 2% of the Cardinal budget. This identifies one of the greatest problems of the Cardinal Center; if it is to serve the residents of Kosciusko County then the contribution from the county's budget should become a larger portion of the Cardinal budget to support the services the Cardinal Agency provides. It is ironic that a sister agency, the Bowen Center, receives direct tax support to serve the emotionally handicapped and then it can also charge its clients or involved agencies. This milige is approximately \$130,000 and is given annually by the tax payers of Kosciusko County. Presently there are no controls locally on how those funds are utilized. Yet the Cardinal Center has to reduce its services which will greatly affect local citizens.

There are many solutions to this problem, if one believes it is a problem. One, legally the county can assess additional milige to four cents per assessed evaluation to generate funding for services provided by the Cardinal Center. There are several potential problems here in that there should be some controls placed on these monies which could still be monitored by the County Council. Another option is for the county to continue its present form of support but to

increase the amount of its support to \$200,000 per year. Again, the Council should have governing control over the Cardinal Center's actions. Ironically, in the late 1970's the county was giving approximately \$60,000 per year to the Cardinal organization but that has been reduced over the years to \$20,000. Another possibility would be the establishment of a joint agency in Kosciusko County which would support both the developmentally and emotionally disturbed individuals in the county. This agency or service could be supported through a six-cent assessment per \$100.00 per evaluation.

If adequate monies are available, the following services could be offered to handicapped citizens of Kosciusko County:

1. Continuation of workshop programming (work skills and training program) for every eligible client with no waiting list.
2. Continuation of the pre-school programming for the developmentally disabled.
3. Continuation of the Adult Day Care Program for any eligible client including nursing home clients.
4. Continuation of the work adjustment program.
5. Continuation of the job placement program.
6. Continuation of the work evaluation program.
7. Reimplementation of the kitchen services.
8. Reimplementation of a residential program.

New and expanded programs which could be offered:

1. Increase the residential program because more and more clients with proper training and schooling will be eligible for this service. This service will also reduce pressures on the families of the individuals.
2. Provide service for geriatric clients in homes and nursing homes.
3. Provide counseling services for any family which has developmentally disabled individuals, birth through any age.
4. Provide continued follow-up services, counseling and employment assistance for individuals who are placed in the community for employment and living.
5. Provide crisis assistance to families and individuals in the community who need assistance because of a developmentally disabled individual.

6. Provide comprehensive recreational opportunities for the developmentally disabled.

These services seem extensive but they are all necessary to provide appropriate programming for these individuals. This type of service values each individual and treats everyone as an individual. This type of service will also give families in Kosciusko County with developmentally disabled individuals a viable option for their son, daughter, brother or sister. Since appropriate services would be available locally, a family would not have to make the emotional decision to permanently separate the family. The advantages of this model would include the opportunity for some of the developmentally disabled to have full and productive lives. Lastly, it would provide for those who presently are being neglected or will become neglected.