

Down Syndrome and Human Dignity - Rights and Opportunities

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The prognosis Down syndrome (DS) individual has improved dramatically over the last 20 years. However, ignorance about DS and negligence of their well being; and discrimination and deprivation of opportunities is still very common and widespread. In a recent survey, most (88%) parents felt that their DS children had been discriminated upon by society. At birth, in about a third of cases news was broken in an unsympathetic, discouraging and disrespectful way. Information provided was inadequate. For infants below 2 years of age, over half indicated they received satisfactory service as a whole. Major complaints were inadequate, uncoordinated services and lack of parental involvement in decision-making. One major concern is antenatal diagnosis. The ethical and legal implications of antenatal diagnosis have not been adequately discussed in Hong Kong.

For school age DS children, they still need a wide range of services. Initial educational placement is a developmental crisis for the family. A quarter of parents expressed that assessment was not fair and accurate. The shortage of manpower in the allied health professions was serious. There was also a lack of choices for schools and educational programs. Despite over 80% of the parents in the survey would like to participate in developing the education program for the child, about one-fifth of the parents did.

Segregation is apparent in many services. Education, community service and employment are still largely a captive environment for DS persons. Hong Kong has just started integrated education in 21 schools after decades of piloted schemes in pre-school system and the English speaking schools. The Child and Youth Centres are still exceedingly cautious of having DS persons as their clients. Employment chances are very limited.

Human dignity should built on equal opportunity, we have to give equal chances to DS individuals as evident from the parental/individual choice, our school and work system and the community acceptance of DS persons.

Genetics in the Community

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Hong Kong Retinitis Pigmentosa Society

As a minority group in the vulnerable community in Hong Kong, no adequate and specific caring is provided to the people suffering from Retinitis Pigmentosa or other inherited retinal degenerative diseases by the government and medical service authorities in the past time. Patients and their family as well as the general public were not able to understand the disorders because of no appropriate information is provided to them. Founded by a group of patients, and with the support and assistance of enthusiastic ophthalmologists, optometrists, geneticists and other individuals, the Hong Kong Retinitis Pigmentosa Society, a non-profit making patients' mutual help charity organization has started to play its role since March, 1995. A major project pursuing by the HKRPS is the Hong Kong Retinitis Pigmentosa Patients' Register Scheme. With joint efforts of the Optometry Department of the Hong Kong Polytechnic University, several ophthalmologists, Clinical Genetic Service, Health Department of the SAR, and the HKRPS, we plan to establish a data base consisting of information of clinical characteristics and family hereditary records of all RP patients in Hong Kong. Phase one of the scheme has been commenced in September, 1998. More than 100 patients and their family members are receiving relevant examinations, diagnosis and counselling. The scheme will be extended to more families and digged into its depth including DNA study if necessary funding is obtained. Genetics may not be the exclusive business of the geneticists. It should be an affair in the community. We shall spare more time on the conventional and updating knowledge of genetics in the primary and secondary schools. It is the high time to seriously consider the establishment of comprehensive genetics studies in the universities here in Hong Kong. Public education shall be developed and enhanced in the community jointly by the government authorities, geneticists, and related agencies in the society.