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IMPLICATIONS OF THE EFFECTS OF THE RUBELLA VIRUS FOR VOCATIONAL PLANNING

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I. INTRODUCTION

The effects of the rubella epidemic of 1963-65 have been well documented in our current literature. It is a pleasure to share some of this information with you, as the time is at hand for us to begin plotting our strategy for providing services to this population. As Dr. Gary Austin points out, the 1963-65 rubella epidemic produced between 8,000 and 10,000 children who were born with hearing impairments (Trybus, Karchmer, Kerstetter, and Hicks, 1980). For rehabilitation, this means increases of as much as 175 percent in the number of young adults who will soon be seeking services. With available funding dwindling across the nation, we will be faced with more clients who need services than ever before. The rubella victims will begin to reach the age of eligibility as early as the next year or two and experts indicate that they will remain in the service delivery system for years to come. As such, the time for understanding and planning is now.

II. EFFECTS OF THE RUBELLA VIRUS

Rubella begins to affect its victims *in utero* when the mother contracts the virus early in pregnancy, particularly during the first trimester. The growing fetus cannot mount an immune response to the virus which produces only mild symptoms in the mother. The virus causes damage to the fetus by destroying cells, reducing the rate of cell division, and producing an inflammatory response. The rubella virus focuses its attack on specific cells, for example one part of the heart, or one part of the eye (Cooper, 1980). As a result, 37 percent of rubella deafened persons have one or more additional handicaps, compared with less than 25 percent of the general deaf population (Trybus, Karchmer, Kerstetter and Hicks, 1980).

There are at least three mechanisms by which the rubella virus causes damage to its victims. In some cases, infants exhibit serious symptoms during the first weeks or months of life. These

neonatal manifestations include bleeding into the skin, hepatitis, anemia, pneumonia, and other serious conditions which can, largely, be treated medically. These conditions are caused by the infection created by the virus and by attempts of the infant's immunological system to battle the virus (Cooper, 1980).

A second category of effects of the virus includes structural or continuing manifestations. Seventy-three percent of the rubella victims demonstrate a significant hearing loss (Chess, Fernandez, and Korn, 1978). Most rubella victims demonstrate a bilateral sensorineural loss with a flat or cup-shaped audiogram (Vernon and Hicks, 1980). There may be a marked difference between the individual's pure tone audiogram and his or her functional level (Vernon, 1969). For example, an individual with a profound hearing loss may actually function more like a hard-of-hearing person, and vice versa. Additionally, hearing loss is often more severe when rubella is the cause of deafness as noted in Table 1.

TABLE 1
Severity of Hearing Loss By Cause

	Rubella %	Rubella Not Reported %
Less-than-severe (70 dB ISO)	15	35
Severe (71-90 dB ISO)	30	24
Profound (91 or more dB ISO)	55	41
Total	100 N = 8,458 ^a	100 N = 41,786 ^b

^aAudiological information not available for 290 rubella students.

^bAudiological information not available for 2,772 non-rubella students.

Many victims of rubella also suffer from cardiac conditions. Vernon, Grieve, and Shaver (1980) note that between 35 and 76 percent of rubella victims have cardiac conditions. The

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two most common conditions, patent ductus arteriosus and ventricular septal defect, can be surgically corrected, but may have lasting rehabilitation and psychological implications. The common cardiac defects associated with prenatal rubella are included in Table 2.

TABLE 2
Some Cardiac Defects Associated With Prenatal Rubella

Defect	Description
Patent ductus arteriosis ^a	Failure of the opening between the aorta and pulmonary artery to close after birth
Ventricular septal defect ^b	The presence of a hole between the two lower chambers of the heart
Peripheral pulmonic stenosis	A narrowing of the large vessels leading from the heart to the lungs.
Atrial septal defects	The presence of a hole between the two upper chambers of the heart
Tetralogy of fallut	A combination of four congenital heart defects
Coarctation of the aorta	A narrowing of the aorta which is sometimes lethal
Truncus arteriosus	The arterial trunk connected to the heart

^aMay be present in as many as 58 percent of children with prenatal rubella

^bMay be present in as many as 18 percent of these children.

SOURCE: Vernon, Grieve, and Shaver, 1980.

A third category of structural damage, visual defects, affects 33 percent of the rubella population, a figure three times greater than that for the general population. Cataracts are present in 20 to 50 percent of infants with prenatal rubella and glaucoma occurs in 4 percent of rubella children (Vernon, Grieve, and Shaver, 1980). Table 3 presents some of the major visual defects that are associated with prenatal rubella.

In addition to neonatal and structural effects of the rubella virus, there are also later emerging consequences which may occur at any stage of the victim's life. These conditions are particularly important in that they require continual monitoring by knowledgeable professionals. For example, more than 50 percent of rubella victims develop some type of urogenital disorder, including undescended testicles, inguinal hernias, defects of the urethra, and narrowing of the urinary tract. Most of these conditions can be managed medically or surgically, but they require that rehabilitation and medical personnel be alert to the possibility of such

defects and that their psychological and vocational implications be considered.

TABLE 3
Some Visual Defects Associated With Prenatal Rubella

Defect	Description
Cataracts ^a	An opacity of the eye lens or its capsule
Glaucoma	A fluid build-up in the eye causing intraocular pressure which can lead to retinal damage and blindness
Microphthalmia	A small but functionally adequate eye
Iridocyclitis	Inflamation of the iris which can cause photophobia
Strabismus	Crossed eyes or wall or wandering eye due to muscle imbalance
Nystagmus	Involuntary twitching eye movements
Viral Ductryodentitis	Inflammation of tear ducts

^aMay be present in 20 to 50 percent of infants with prenatal rubella.

SOURCE: Vernon, Grieve, and Shaver, 1980.

Similarly, endocrine disorders are common in the rubella population, including diabetes mellitus, hypo- and hyper-thyroidism, and disturbances in adrenal gland function. These disorders may not emerge until the teenage years or later. For example, 15 to 40 percent of teenagers with prenatal rubella develop diabetes mellitus, with some researchers noting an even higher incidence of pre-diabetic conditions (Vernon, Grieve, and Shaver, 1980).

Perhaps the best-known, later-emerging consequences of prenatal rubella fall within the category of psychoneurological sequelae. Chess (1977), Vernon and Hicks (1980), Chess and Fernandez (1980), Hicks (1970), Vernon (1969), and Vernon, Grieve and Shaver (1980) have all documented the effects of the rubella virus on psychological and neurological processes. Chess and Fernandez (1980) feel that these effects may be the most significant of all from an educational and vocational perspective. The rate of mental retardation in the rubella population is 42 percent (Vernon and Hicks, 1980). Similarly, autism is significantly higher in this population, approaching 7.4 percent (Chess, 1977). Aphasia and severe learning disabilities may also be present, as indicated in research by Feldman, Lajoie, Mendelson, and Pinsky (1971), Jensema (1974), Lehman and Simmons (1972), and Vernon (1967, 1969). Interestingly,

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Chess and Fernandez (1980) indicate that such conditions as retardation and autism may be variable over time, e.g. a child diagnosed as mentally retarded or autistic may later be found to be free of these conditions and vice versa.

Chess and Fernandez (1980) note that behavioral disorders are half again more common in the rubella population than the general population. They note that behavioral disturbances may occur either because of chronic brain syndrome or as reactive behavioral disorders. In the first case, damage to the brain has a direct effect on the individual's behavior, producing such symptoms as perseveration, difficulty in shifting from one task to another, sudden shifts in mood, overreaction to stimuli, and high distractibility. In the second condition reactive behavioral disorder, the individual reacts to the stress created by motor and perceptual difficulties and may have difficulties coping with tasks and establishing interpersonal relationships. While both types of behavioral disorders can be dealt with medically and through therapy, Chess and Fernandez indicate that the etiology of the behavioral disturbance carries significant implications for the choice of treatment approaches.

Impulsiveness is one behavioral trait which has been often cited as a characteristic of the rubella population (Chess and Fernandez, 1980; Hicks, 1970; Vernon, 1969). In an interesting study, Trybus, Kerchmer, Kerstetter, and Hicks (1980) studied the number of reportable behavioral incidents at the Model Secondary School for the Deaf by etiology of hearing loss.

TABLE 4
Reportable Behavior Incidents At MSSD
By Cause Of Hearing Loss

Item	Rubella ^a	Other Causes ^b
Percent with one or more reportable incidents	40%	99%
Average number of incidents per person for those with one or more incidents	2.7	2.2
Percent of incidents involving violence	42%	31%

^a111 rubella students

^b91 students deaf from other causes

SOURCE: Trybus, *et al*, 1980

As the data presented in Table 4 demonstrates, less than half as many students with

rubella as the cause of deafness were involved in reported behavioral incidents than were students with other etiologies. The average number of incidents per person for those involved with one or more incidents was slightly higher for the rubella students. However, the percentage of incidents involving violence was somewhat higher for the rubella students. As such, the likelihood of acting-out behaviors appears to be lower for rubella students although the severity of the episode may be greater.

Finally, Trybus, *et al* (1980), have presented interesting information regarding the mean achievement scores of students at the Model Secondary School for the Deaf.

TABLE 5
Median Achievement Scores For MSSD Students
By Cause Of Hearing Loss

Item	Rubella ^a	Other Causes ^b
Reading Comprehension (median)	138	146
Math Computation (median)	166	167

Although reading scores are somewhat lower for the rubella students in Trybus' data, he speculates that this may be due to more severe hearing losses and a higher incidence of additional handicapping conditions. Jensema (1974) reported no significant difference in achievement test results between rubella students and those with other etiologies. These data refute the misconception that rubella children lag substantially behind their peers in the area of academic achievement.

III. IMPLICATIONS FOR VOCATIONAL PLANNING

The research available regarding the children born during the 1963-65 rubella epidemic clearly demonstrates several problems which must be addressed if we are to successfully plan for appropriate rehabilitation services for this population. First, the sheer number of potential clients who will need rehabilitation services is staggering. In an era of dwindling resources, it is unlikely that we will be able to hire additional counselors and develop new programs to meet the increased caseload which may begin as early as next year. This is not a population that we can ignore and simply hope to hold our ground until they have passed through the system. As the

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impact of this rubella "bulge" is likely to remain with us for many years to come, hard decisions must be reached at every level of the rehabilitation system regarding priorities and strategies for serving this population.

Second, research indicates that this is a much more diverse population than we originally believed. Many experts who addressed the 1980 conference on rubella and deafness believe that the first rubella graduates may be on a par academically, socially, and psychologically with "average" or "typical" deaf clients. Although born within months of each other, the rubella students have been spaced over four or five years of academic placement. Many experts feel that each succeeding graduating class will present more difficulties for rehabilitation. Thus, the first graduates may have few, if any, difficulties in addition to their deafness, whereas succeeding classes will consist of the more severely involved students. As such, we will need to effectively utilize all of our current service delivery network, including post-secondary pro-

grams, vocational training and rehabilitation services, sheltered workshops, and mental health facilities. This need is apparent in data generated by Stuckless (1980), which depicts projected activities after graduation for 1980 graduates.

The complex physical conditions related to prenatal rubella also have implications for rehabilitation professionals. The rehabilitation counselor serving deaf clients (especially the RCD) can no longer afford to limit his or her competencies to deafness and rehabilitation. In-service training is needed to familiarize counselors with other commonly occurring effects of rubella, including visual defects, cardiac conditions, endocrine disorders and urogenital defects. Counselors will also need to develop professional resources that they may not have seen a great need for in the past, including cardiologists, ophthalmologists, urologists, psychologists and psychiatrists, and endocrinologists.

It is unlikely that we will be able to meet the needs of this population given that additional resources appear to be unlikely at this time. We will need to build alliances with facilities and specialists serving the general handicapped population, as well as other specific disability populations. We will need to share our expertise in deafness with them and open ourselves to learning from their experiences as well.

Finally, there is a need to establish regional and state task forces to begin planning for this population now. We can no longer afford to talk about "those rubella children in the schools", for those individuals will soon be young adults seeking our assistance in establishing a productive and meaningful role in society. Perhaps the challenge of meeting the needs of this unique population will enable us to utilize our available resources in a more effective manner, thereby resulting in an improved service delivery network for all hearing impaired persons.

TABLE 6

Percentage Distribution Of Projected Activities Of 1980 Seniors and Rubella Students After Graduating From Secondary Programs For The Hearing Impaired

Projected Activities	1980 Seniors	Rubella Students
Enter bachelor or associate degree program	37%	30%
Enter non-degree program	19%	22%
Subtotal, postsecondary program	56%	52%
Directly enter labor force	30%	35%
Substantial Rehab. services (good prognosis*)	8%	9%
Continuing care (poor prognosis*)	6%	4%
Subtotal, major rehabilitation needs	14%	13%

*Prognosis for future independence

SOURCE: Stuckless, 1980

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