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Down syndrome revisited

H Patzer

Kinderklinik der Medizinischen Akademie Erfurt, GDR

Down syndrome has been known for a long time. Today Down children are mostly cared for in boarding facilities for patients with different handicaps. As a result, it is often neglected that Down children have a unique specific personality. To call attention to it was the aim of the present paper.

We are accustomed to classify a large group of children under the term "disabled" or "handicapped". The term stands for an impairment of their active conduct with the social and natural environment due to congenital or acquired damages. In recent decades many institutions and facilities for diagnosis, registration, therapy and, especially, complex care of handicapped children have been created by physicians and teachers. Working with the disabled involves, on the one hand, some general principles irrespective of the type and locus of damage. On the other hand, however, the special pattern of any impairment has to be taken into account in order to adapt properly the scope of measures to the abilities and limitations. The following pages are meant to recall the special features of a syndrome that has been known for a long time.

It was almost 120 years ago, when Langdon Down tried to classify from an ethnic point of view the oligophrenic conditions which were known to him. Concerning a certain type with facial signs resembling those of Mongolian tribes he called it "mongoloid".

Though in the following this approach has proved erroneous, it remains Langdon Down's merit to have discovered the somato-psychic entity of the snydrome with its peculiar character. Later the condition was renamed Down syndrome.

Today it is impossible to decide whether mongolism occurred more often at that time than in our days and it was therefore that it attracted attention or whether it only was diagnosed more often after medical interest had once been awaken. In paediatric textbooks of the first decades of our century mongolism has its safe place. It is described as a clearly defined type of infantile oligophrenia with special somatic stigmata (Fig. 1) and a typical kind of behaviour.

Deeper insight into the essence and personality of mongoloid children

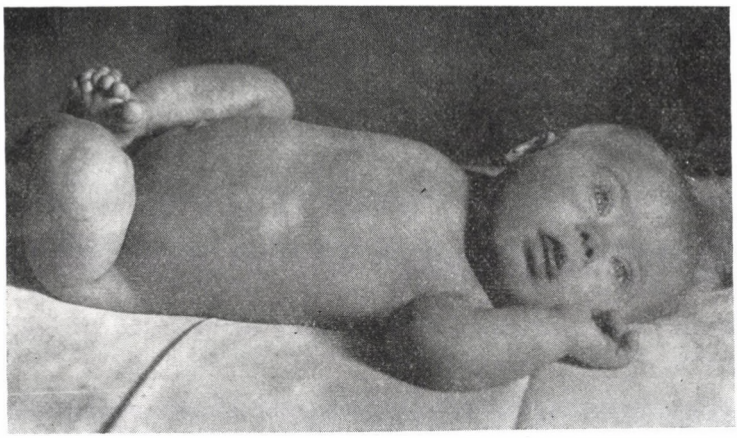

FIG. 1

was gained at that time especially by teachers who made great efforts to educate their pupils who often lived in close community with them. In this connection, the ideas of Rudolf Steiner's anthroposophy played an important role. Concerning the aetiopathogenesis of Down syndrome, doctors at that time had no more than speculative ideas. As early as 1932, Waardenburg assumed an error of the genetic information during ontogenesis. Simultaneously and independently, in 1959 Ford, Jacobs and Lejeune found trisomy 21 to be the cause of the disorder.

With that discovery, mongolism grew into a favourite subject of human genetics. Even if the essential cause of the disease remained unknown, it lost something of its mistery. The situation of parents of mongoloid children and the work of people responsible for the care and education of hadicapped children have not become easier. On the contrary, it may have been complicated by our modern attitude which classifies the mongoloid child together with many others into the large group of the "handicapped". Doing so one often neglects the fact that the structural change of personality in mongolism is more marked than in any other somatopsychic developmental disturbance. This is illustrated by the fact that the diagnosis is not based on a single symptom but on the general appearance (the German term for which is "Gestalt").

König [1] called it "a peculiar kind of human existence determined by regressive tendencies". We must be aware of this complex and profound disturbance of personality differentiation rather than to look for an impairment of single functions when dealing with mongoloids. Their integration into the human community is thereby restricted, as was argued by König. On the other hand, knowledge of the urgent need of mongoloids for adequate social conditions is also important.

Keeping these premises in mind we should trace the tasks of care for mongoloid children and their parents at some important stages. It is needless to stress how intricate and responsible is the first talk of the physician with the parents. It is often overseen that this first talk with the mother alone, without her husband, whom she herself has then to inform afterwards, means an almost unbearable psychic strain to her. We have learnt from talks with mothers that this situation belonged to the hardest experiences in their lives being additionally aggravated by feelings of guilt, although we know that these cannot be justified objectively.

Mongoloid children require continuous human warmth of the paediatrician and contact with them. With regard to medical care proper, there are no differences between healthy and mongoloid infants in their first year of life. Thanks to modern therapeutic means, the risk of bronchopulmonary infections has decreased significantly. Quietness and the unassuming manner of mongoloid children must by no means lead to a passive attitude which would leave their motor and social development to itself. Beyond any doubt, carefully guided parents are the best therapists at this age. We have a wide system of social assistance, involving helpful measures for the families of these severely handicapped children and adolescents.

In most cases, parents are elder people with human maturity, patience and understanding. It is necessary to encourage them and in many cases it would be best if they acted according to their feelings and experience. Quite special physiotherapeutical measures are not even necessary.

In our country 70% of all mothers go to work. Their children are put up in creches (day-nurseries). During the first year of the child's life the mother can interrupt her job in order to deal only with bringing up and educate her child. The first year is especially important for mongols. Later on, when the mother resumes her profession and accommodates the infant in a creche for several hours a day, it becomes obvious that even under good conditions the mongoloid child has significantly remained behind in his motor, speech and social development. According to the comprehensive observations made by König [1], speech and thinking are not as developed as necessary to permit a systematic education to be started.

Education of mongols within an age-matched group of normal children is almost in vain. They are gathered, therefore, in special groups of handicapped within creches or kindergardens for normal children.

Specialist teachers and nurses together with the parents strive for their advancement there. Once again it becomes evident that mongols cannot be compared to any other child. We fully agree with König's statement when he says that "the basic way of behaviour of the mongol consists in imitation, and actually in an exaggerated readiness for imita-

FIG. 2

FIG. 3

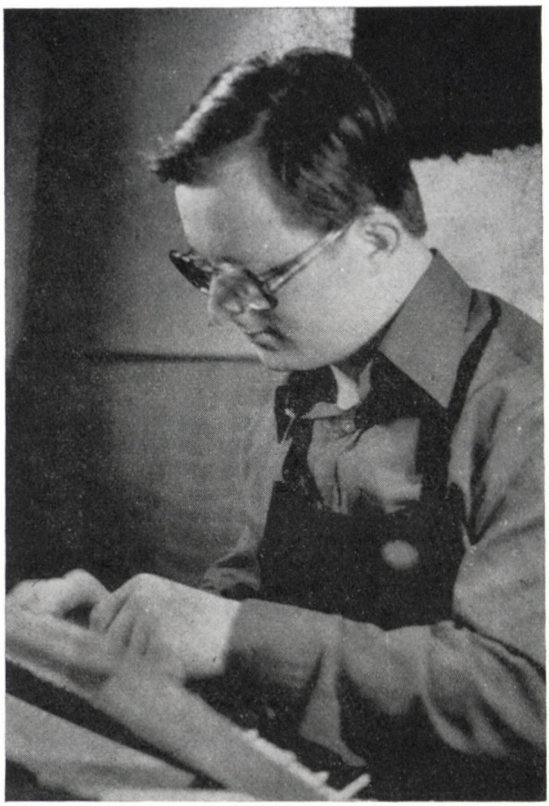

FIG. 4

tion" (Fig. 2). This is favoured by the lack of speech. Thereby, the mongol often appears restless and hyperactive. On the other hand, his ability to take up and make use of environmental impressions is often overestimated.

In general, in mongoloids speech and thinking are not as developed as to set off a learning process comparable with that of a normal child. They seem to have a good memory. Thus, the child identifies letters and words but has no essential understanding of the meaning of figures. It "understands", in the strict sense, less of the environment than its behaviour seems to indicate. That is why the mongol remains much more dependent on, and open to, every kind of influence than are other children. On the other hand, this susceptibility can be used to facilitate the education. They like, e. g. to deal with dyes, textiles (Fig. 3), wood and other materials. Their well-known pleasure in music, especially in rhythm, can well be used to further their motor development.

Whether the education of mongoloid children and adolescents occurs in a special school or in a boarding

facility without school-type education is not really important. The main task is to prepare them for the daily practical life, and to fulfil their need of joy and communication.

The definite limits of development to a full human existence become obvious after puberty at latest. The body remains undifferentiated, mental development stops, a premature aging process begins. Almost none of these children attain social independence. Many families, however, make it their task to give adolescent or adult mongols love, care and safety in the family community. In boarding facilities and other caritative homes mongoloid adolescents and adults are mostly quiet and relatively unassuming inhabitants (Fig. 4).

I do not want to make the impression as if I would be resignated about the possibility of education of mongoloid children and adolescents. But we should recognize and honour their characteristic, though limited, way of human existence. This is the only possibility to diminish our huge obstacles and difficulties in living together with mongoloid people.

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Prof H Patzer
Am Schwemmbach 32a
5080 Erfurt, GDR