ORTHOPEDAGOGIC INTERVENTION FOR A CHILD WITH SPINA BIFIDA*

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I HISTORICITY

Three months after a miscarriage, the mother became pregnant with Fannie.[1] During her pregnancy, at 3 months, and again at 5 months, there were threats of miscarrying. After a normal birth, the baby of 2.4K (5lb. 4oz.) was born with Spina Bifida and Hydrocephalus. When a child is born with Spina Bifida, the spinal column is not completely closed and part of the spinal cord protrudes. This usually occurs in the lumbar region of the spine. Depending on the part of the spinal cord exposed, the child, to some degree, will be crippled, and have numbness in his/her lower limbs. Usually, this is paired with Hydrocephalus (water head).

In Fanie's case, the spinal cord and nerve roots are exposed and at birth, his cranium already exceeded the normal limits by an inch (2.5 cm). When he was 9 hours old, an operation was performed to close his defective back, and when 2 weeks old, a ventricular valve was implanted in his skull. Excessive brain fluid drained through the valve into a subcutaneous tube from the skull to the periodontal cavity, where the liquid is absorbed. In this way, excessive pressure on the brain is relieved. [The child never gained control over urinating and defecating. His lower body, and the extreme parts of his legs and feet are numb].

According to the parents' information, the milestones were extremely delayed. Fanie sat at 5 months. and crawled at 10 months. At 22 months, he succeeded in learning to walk with special boots and iron knee supports. However, his balance was

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[1] See the hypothesis of Cyril Clarke et al. regarding possible causative factors of Spina Bifida as discussed in an article "Spina Bifida and aanencephaly: miscarriage as possible cause" British Medical Journal, 27 December 1975, Vol 4, pp. 743-746.

extremely poor, and he could not feel when his little feet got caught on something or were bent backward. Consequently, he fell often and moved with extreme labor. An additional factor which restrained his mobility was that he increased in size very quickly. This appears to be a general problem with children who have Spina Bifida.[2]

There were no feeding problems, but until 2 years, Fanie walked continuously with a baby blanket in his mouth. The parents were dissatisfied with this situation but could not bring him to stop doing it. (This is an early indication of their awkwardness in exercising and maintaining authority with their child).

Just after Fanie's first birthday, the excess forming of liquid in the skull stopped, and it was no longer necessary to use the ventricular pump.

At 2 years, he underwent his first foot surgery when it was found that he could move one of his big toes. A pin was placed in the toe to try to increase the mobility of his ankle. However, the operation failed.

At 3 years, he had an accident with a pair of garden shears during which he lost the first joint of his left middle finger. The parents interpreted this accident in such a way that, from then on, they kept him away from all scissors, knives, pencils, and other objects with which he possibly can hurt himself. The overprotection, which had arisen from the parents' feelings of guilt, resulted in a serious limitation in his possibilities for experiencing, exploring, and emancipating himself.

At 4 years, Fanie had a serious spinal infection which was accompanied by a persistently high fever. The subcutaneous tube was a contributing factor to the infection, and was removed, but the valve was left in.[3]

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[2] Dorner, S.: The Relationship of Physical Handicap to Stress in Families with an Adolescent with Spina Bifida" in Developmental Medicine and Child Neurology. 1975 Vol. 17, p. 769.
[3] See the article by Hunt, G.M. and Holmes, A.E. in which they indicate the connections among a ventricular pump, infection and intelligence. "Factors relating to Intelligence in treated cases of Spina Bifida Cystica". It seems that where children with Spina Bifida have had an inflammation of the central nervous system, intellectual retardation usually is present. American Journal of Diseases of Children, Vol. 130, August 1976, pp. 823-827.

At 5, Fanie underwent an additional foot operation, and at 6 years and 2 months, he entered an elementary school where he was placed in grade one.

II STATEMENT OF THE PROBLEM: THE DILEMMA OF EDUCATORS IN THE PRIMARY (HOME) AS WELL AS THE SECOND ORDER (SCHOOL) PEDAGOGICAL SITUATION

THE SECOND ORDER EDUCATIVE EVENT

Within three months of his school career, Fanie and his teachers were in a troubled educative situation.

The relationship of trust between teachers and child had gone wrong because of his continuous insistence for individual attention. He was not at all ready to join group activities, and it was continually experienced that the teachers had left him in the lurch.

The relationship of understanding similarly failed because of a defective knowledge and insight of the classroom teacher regarding this unique child's historicity, his level of becoming, and his unique experiential dispositions. Also, there was a deficient understanding of his place in the class, and the limits of the individual support and attention which he could expect.

The relationship of authority between teacher and child, at first had serious failings because of the defective underlying relationships of trust and understanding, but in due course, it got better as the affective and normative guidance by the teacher improved. Although cognitive guidance was adequate, the actualization of his cognitive potentialities was defective, among other reasons, because of his inadequate intention to learn, and physical limitations in his involvement with the learning material. Because of the classroom teacher's lack of understanding of the nature and extent of his handicap, her choice of examples and reduction of the learning material failed in making reality accessible to him. Also, because of his affective distress, he was unable to throw himself open to the learning material. Thus, the didactic event miscarried.

Fanie directed himself with abandon to establishing relationships with his classmates. In contrast, because of his physical impediment and conspicuous "otherness", the other children shied away from him, and he never was admitted to the "our space" of the class group. His limited mobility was a prominent factor here. From a socio-pedagogical perspective, he was involved in distressful becoming.

The following progress report was presented to the parents by the school at the end of the first school term:

1. Visual discrimination – good.
2. Visual memory – poor; e.g., cannot associate numbers with aggregates of objects.
3. Auditory discrimination – finds it difficult to distinguish between similar sounds.
4. Auditory memory – good. Knows some short rhymes but has little success with sounds (alphabet).
5. Eye-hand coordination – poor. Can barely master this after much practice.
6. Has a laterality problem, e.g., working with scissors and paperwork.
7. Emotional development – slow in carrying out assignments (would rather play with educational toys).
8. Attention fluctuation – quickly tires.

The school's educative problematic, rightly, is labeled an orthopedagogic event where educator and child are involved with each other in a confusing situation which leads to his not progressing in his becoming as he should.

THE PRIMARY EDUCATIVE EVENT

The physical caring of this handicapped child has placed a heavy burden, especially on the mother-son relationship. His mother had to drive to school daily to change his diapers.

Because of his size, clothing, and especially the availability of moisture proof underwear, was a major problem. The family's social activities and vacations were drastically limited because of the

nature of Fannie's handicap. Indeed, the entire household was organized to accommodate him. This gave rise to excessive intervening with him, spoiling him, and an excessive obsession with cleanliness, and physical appearance.

The degree of misconception of the parents about the unique situation of their child seemed clear from the fact that they defined him as an ordinary boy who must wear diapers. Consequently, they also were determined to let him follow an ordinary school course, where he could be "like other children".

Fanie's parents continually denied reality by convincing themselves of their child's superior intellectual potentialities, and by holding out to him an academic course as a future perspective. They gave him the impression that one day, he also would be able to play rugby and wear "pretty" shoes.

His parents also were seriously shocked when they heard that he did not wish to progress with his schoolwork. On recommendation of the neurosurgeon, they sought orthopedagogic help, with the request that they be presented with findings about their child's potentialities and be given advice regarding his further educating.

Thus, the orthopedagogue was confronted with the question: How to now proceed further with this child?

III ORTHOPEDAGOGIC INVESTIGATION

1. Observation image

The Father:

During the exploratory conversation, the father was tense and wanted to put Fanie in the most favorable light possible. He emphasized the excellence of his language potential, and the range of his penetrating questions. He refuted point by point the findings of the teacher and continually brought the mother into the account to state things in a more euphemistic way. It was obvious that this father seldom answered questions about Fanie spontaneously. He

continually reflected on or asked counter-questions to try to determine which answers would give the most favorable impression of his child. With respect to Fanie's motility and intellectual potentialities, he tried to give a favorable account.

The close affective bond and the great amount of daily intervention between this father and Fanie were striking. The father spared nothing in coaching and training his son in ways of behaving, which would make him appear to be more acceptable. At the beginning of the investigation, he insisted that Fanie was able to walk the distance to the site of the investigation, even though he continually had to rest, sweated from the effort, and stumbled and fell repeatedly, even while is father held his hand tightly.

The father indicated his dissatisfaction with the classroom teacher's misconceptions, as well as with some of the medications which had been used to treat his child in the past.

There was a close bond of identification between this father and his son. It gave him great pleasure to point out that physically, they looked very much alike.

The Mother:

She was somewhat more objectively attuned to their child's present situation, but continually tried to make the practical problems seem small. Also, it seemed that her future expectations for Fanie are unrealistic. She did not accept his defect as a permanent limiting factor, and had little insight into the implications of his unchangeable physical deficiencies.

It troubled Fanie that her relationship with him now was more distanced. and that he was disobedient. She hesitated to discipline him, and was aware that he exploited the situation. When the father objected to her attempts at disciplining, she let him have his way and, in this way, she submitted to him.

The mother gave the impression that she was prepared to fathom their problem situation with an open mind, but she continually allowed herself to be influenced by the father.

This woman's daily routine revolved around caring for her child. Each day she spared nothing in transcribing his daily school assignments, and duplicating them with him at home.

The Child:

Fanie was extremely overweight, but his head did not appear to be excessively large. His mouth's outer corners were conspicuously higher than the inner ones, and it hangs open. His hands were short, and fat, and his finger muscle coordination was poor. He could not maintain his balance if he stood and fell easily if he walked without help. Physical movement was a great effort for him, and he sweated easily. His upper legs were thick in relation to his lower legs, and his feet were noticeably small. He wore iron knee supports, but moved very laboriously, while the left foot was turned outward and trailed slightly.

Fanie distanced himself from his parents without difficulty, and he smiled readily when addressed. However, he had difficulty arriving at an authentic encounter, and only communicated superficially. He continually appeared to be confused. He refused no assignments, and he continually tried to carry them out and meet their requirements, but his actions very quickly deteriorated into disordered confusion.

Fanie was hyper-distractible, especially acoustically. His attention span was particularly short and, in addition, his attending declined. He was aware of his extreme appearance, and was concerned that his hands and clothes stay clean.

He did not attain a real involvement in the research situation and gave the impression that he always would follow the path of least resistance. He continually asked for help, even with tasks which he previously carried out successfully. Fanie had no desire to break away from a lack of exertion.

Fanie was a well-mannered boy who, without opposition, behaved courteously in compliance with the demands of propriety which addressed him from his cultural milieu. For, example, he knew

various child prayers, and could count fluently (without understanding numbers) and, on request, he drew stylized drawings such as his father trained him to do. It was a great chore for him to imagine and fantasize for himself.

2. Intelligence image

On the Individual Scale of the National Bureau for Educational Research, he obtained an IQ of 90, with a mental age of 5 years 10 1/2 months. This medium ("test") is primarily verbal. Of the 28 items up to the 6-year level, only 7 require a non-verbal response. Some of the items dealt with those aspects in which his father had trained him. Also, this presumes a certain possessed experience. This child has led an extremely sheltered life, and was exposed to little of the surrounding reality.

For the sake of greater clarity, the National Bureau for Educational Research's Group Scale for five- and six-year-olds was also administered. This is a paper-and-pencil medium and requires exclusively Non-Verbal responses. This medium is not so culturally bound and makes an appeal to a child's potentialities for abstract thinking, drawing logical inferences, perception, motor and other potentialities which are related to school readiness.

On this scale, he fared considerably more poorly, and achieved an IQ of 76, with a mental age of 4 years and 8 months. His percentile rank was 8. "A percentile rank is described as a point on a 100-point scale which indicates the percent of scores falling below it. In other words, it indicates what a test person's position will be in a representative group of 100 of his own age-mates, if they are put in order from the lowest to the highest score".[4] Fanie's score of 8, thus, indicates that 92% of his age-mates scored higher than he did.

It appears that there is a large difference between his Verbal and Non-Verbal achievements.

Poor motor skills are a limiting factor for children with Spina Bifida. Because of his poor balance, he also had directional uncertainty, as

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[4] National Bureau for Educational and Social Research. Handbook for the N.B. Group tests for five- and six-years and for seven- and eight-years, p. 24.

well as poor form constancy, and a defective insight into spatial relationships. In his thinking, he remained mostly bound to the concrete, and his unordered lived experiencing of reality led to him not working systematically, and to stagnating on a trial-and-error level.

Neither of the IQ scores can be viewed as trustworthy in this case, and the possibility cannot be eliminated that his intelligence is more favorable than what the scores indicate. Because of the state of his educating, his physical restraint, and defective life experiencing, he actualizes his intellectual potentialities inadequately, and an IQ of 90 is viewed only as an indication of his current achievement. Correctly, Hunt and Holmes say, "Most severely handicapped children suffer from lack of experience due to their restricted activities, and these factors must be taken into account when assessing their developmental level".[5]

3. Expressive and projective image

To be of help to this child where he is, and as he is, it is necessary to penetrate his experiential world to arrive at an understanding of his unique attitudes [positions] toward the contents of his world.

The following media are used:

a) Verbal projective media: South African Picture Analysis Test (S.A.P.A.T.)
b) Graphic projective media: three trees- house- and person-drawings
c) Play projective media: The Sceno-Test of Von Staabs, and free-play with toys of his own choice.

The following emerged from these media:

(i) Defective cognitive control which gave rise to confusion with respect to ordering life reality. Fanie arrived at a diffuse impression of the whole

[5] Hunt, Gillian M, and Holmes, Alex E, "Factors Relating to Intelligence in Treated Cases of Spina Bifida Cystica" in American Journal of Diseases of Children. Chicago, p. 826.

and then stagnated. He did not proceed to analyze and synthesize.

(ii) Gender confusion. Indeed, he knows he is a little boy but his future perspective and the man-woman relationship is vague and undefined.

(iii) Rejection of mother-son relationship with related feelings of guilt and animosity.

(iv) Lived experiences his low energy level and physical exhaustion.

(v) Strong positive willing.

(vi) Strives to conform.

(vii) Unable to achieve on the level he sets for himself.

(viii) Life uncertainty and unrealistic future expectations.

(ix) Self-centered.

(x) Favorable disposition for affective lived experiencing.

4. Summarized person image

Fanie, as a unique person, has certain personal potentialities which he ought to transform with the support and guidance of his educators.

However, he shows a handicapped becoming, and communicates on the level of a four to five year old toddler. The gap in becoming is attributable to his physical limitations, the state of his educating (problems of guidance), and his own inadequate giving meaning (problems of self-actualization).

a) *Unchangeable physical defects:*

The child is incontinent, and his neuromuscular deviations are not medically treatable. Experience teaches that most Spina Bifida children gradually become less mobile until they eventually are confined to a wheelchair.[6]

[6] See the findings of (i) C.D. Theron as discussed in a talk "Buitengewone onderwys met spesifiek verwysing na die fisiesgestremde Kind" [Special teaching with specific reference to the physically restrained child] presented during an Orthopedagogical Symposium at the University of Pretoria, 1976; (ii) K.M. Laurence and A. Beresford, "Continence, Friends, Marriage and Children in 51 Adults with Spina Bifida" in Developmental Medicine and Child Neurology, Vol. 17 case appendix 35, 1975, pp. 123-128.

He shows growing losses in perception, which restrain his learning, and perhaps he has below average intellectual potentialities.[7]

b) *Guidance problems*

The parents, indeed, have been successful in affectively guiding their restrained child to realizing his personal affective potentialities. Emotionally he gives meaning to reality as can be expected of a child of such an age, and he shows none of the negative emotional expressions which often are found in children with Spina Bifida.[8]

Fanie's emotional interpretation of himself, however, is unrealistic. In response to the pedagogical agreement of the parents for a limited degree of pedagogical intervention, he has an exaggerated view of his own achievements. The parents find it difficult to discipline him, and they praise him so liberally that he has not acquired an authentic self-knowledge, and has not established a place for himself in the social environment.

On a cognitive level, the parents' guidance progressed less favorably. By spoiling, excessive intervening, and overprotecting, they controlled their child's opportunities to explore so much that he is not able to emancipate himself. His questions have the appearance of being insightful while, indeed, they are extremely poor, and superficial and, in reality, they are attention seeking.

By repeating and practicing, Fanie has mastered certain behavioral expressions, but he fails in assimilating them and adding them to a consolidated possessed experience.

The unsuccessful course of the fundamental pedagogical structure of understanding leads to him not having any firm

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[7] This is in agreement with the findings of (i) S.Dorner, "The Relationship of Physical Handicap to Stress in Families with an Adolescent with Spina Bifida" in developmental Medicine and Child Neurology, Vol. 17, 1975, pp. 765-776.
[8] According to S,Dorner, "Adolescents with Spina Bifida", Archives of diseases in childhood, 1976, Vol. 52, pp. 442-444 despondency is a general problem especially in the case of seriously restrained younger patients who are treated surgically. Previously only children with a slight deviation attained adulthood.

beacons in terms of which he can explore and interpret what is strange or unknown. This contributes to his unordered involvement with what is new, and explains his conspicuous confusion.

The parents' normative guidance is qualitatively poor, and is little more than the training of social usages. With Fanie, there is no indication of norm identification. He stagnates on the level of personal identification, and then only with his father. He does not follow the norms his mother exemplifies, and presents to him. The parents do not grant him any opportunity to take responsibility, or to make choices. Thus, it seems clear that the greatest deficiencies in the parents' educating their child are in the pedagogical aim structures.

c) *Problems of self-actualization*

Because of his attenuated possessed experience, and the poor state of his educating, Fanie directs himself to his world in inadequate ways. He does not make use of or develop his positive potentialities, and remains bogged down in complacency.

IV RECOMMENDATIONS

For Fanie to be able to attain the level of adulthood allotted to him [by his restraints], the following orthopedagogic interventions are recommended:

a) Educator guidance: By regular contact, the parents must be supported to see their child in his being different, which arises from his specific being restrained, and his unique personal realization. They must be informed about the essence and aim of educating, and how this ought to be fulfilled in their unique case with specific contents.
b) Pedotherapy with the child with the aim of redefining reality and, more specifically, his unique place and role in it.
c) Milieu change: The educative impeding factors stemming from the child's faulty school placement must be discontinued by transferring him to a school for physically handicapped,

where his physical and medical care can be coordinated with his scholastic progress.

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