

# Advance in Psychology and Education

## The emergence of the psychological life of the child with Down syndrome: reflections regarding early intervention

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### Abstract

The age range with which early intervention specialists work enables them both to witness and support the construction of the subjective self process in children with Down syndrome (FCSD). Viewing development as a dynamic process, this article looks at what conditions are necessary to help the baby/child grow into adult life and reviews the way in which the child's psychological life emerges from the parent-child relationship. Lastly, it considers aspects believed to be important in the emotional development of the child with Down syndrome (DS) on the basis of experiences in early intervention.

**Key words.** Down syndrome. Early intervention. Construction of the subjective self. Emotional development bond.

Studying child development is always a complex task since growing up entails psychological, environmental, social and physical/biological processes. If we look at development as a dynamic process that enables all human potential to flourish (including language, reasoning, thought, memory, attention, emotion and socialisation), it is patent that in order for growth to take place there must be an underlying substrate, and this core develops through progressive construction of the subjective self as well as relationship and communication skills.

Therefore, as Moretti has argued (1), in order for a child to grow successfully into an adult, the child must:

- construct an understanding of the world during early childhood
- construct her 'self'
- share ethical and behavioural codes
- have mature object relations
- employ appropriate thought strategies
- obtain positional socialisation models from reality rather than fantasy

However, the setting must be appropriate and physical and mental health sound if a child is to achieve these aims.

Focusing on the psychological factors, we shall firstly consider what dimensions must be taken into account in order to provide an appropriate setting and what occurs when the child's physical or mental health does not live up to prior expectations, for instance in the case of a child with Down syndrome (DS).

In order to review the psychological aspects that have a bearing on the growth process, we must begin well before birth. From the psychological point of view, one thing precedes the future baby: the parents' desire. An array of motives underpin the wish to have a child, each of which is thought to a greater or lesser extent to trigger the parental bond (firstly mental and subsequently physical) with a baby.

Brazelton and Cramer (2) highlight the following drives:

1. Identification (with mother and father figures)
2. Satisfaction of various narcissistic needs that

allow us to develop and maintain a self-image: the wish to be complete and omnipotent, the desire for fusion and oneness with another, the wish to mirror oneself, the fulfilment of lost ideals and opportunities, and so forth

3. Attempts to recreate or rekindle past bonds in the new relationship with the child.

During the nine months of pregnancy the parents-to-be have the chance to prepare themselves, not just physically but also psychologically. When the expectant mother first feels the foetus move (around the fifth month), early attachment begins and the foetus starts to become an independent being.

It is also important that the father be acknowledged in his role, as this will help the expectant mother separate herself from the foetus and draw a distinction between the baby and her own fantasies. Moreover, she will be reassured by the knowledge that she will not be solely responsible for any successes or failures.

With the arrival of a new family member the father has little choice but to accept the shift from a dual to a triangular relationship, in which he may feel like the outsider. The father's attitude during the pregnancy, birth and early attachment help the mother to adapt fully to her new role.

The psyche of the child is underpinned by the relationship she strikes with her parents. Nevertheless, for psychological development to take place, the child's biological needs and, more importantly, emotional needs must be met, as it is through her relationship with the Other that the child structures herself. It is the Other – the mother figure – who initially organises the baby's body and life by giving her food, hygiene, sleep and so forth. The mother, in her everyday care of the baby, interprets and attaches meaning to his or her demands, and this is absolutely vital for the child to develop. The mother helps her child to organise herself in perspective, movement, social and symbolic terms. Thus, the mother brings the child into a symbolic world where her subjective world based on her upbringing will come into play.

Nevertheless, the parents are not the only parties responsible for bonding with their newborn: baby is also an active participant in early interaction. Just as baby's appearance triggers a response from the parents, baby herself responds to an individual behaviour pattern that was formed in utero. Individual differences between babies affect the way in which they will take part in early interaction and the way in which the parents will

respond. However, the individuality of the baby does not always match the family's ability to deal with her since parents also have personality features that can put a limit on the type of baby they are able to handle.

Taking our consideration of the psychological factors that come into play in this early process a little further, let us now examine what happens when the newborn has some kind of disability or disorder, in this case DS.

On learning that their baby has Down syndrome, many parents are affected not only by the diagnosis, but also by the intensity of their initial reactions and feelings towards the newborn and towards themselves.

For Cunningham (3), parents go into shock which can last for mere seconds or go on intermittently for days when they are given the news. When they begin to react, most seem to experience two fundamental, instinctive feelings:

- a desire to protect their defenceless child
- rejection of their abnormality

Although these two reactions are very 'normal' in that they are present in almost every case, it is still vital to acknowledge them and their consequences because this is an extremely intense and critical time that can have a profound impact on outlook. It is a time when parents oscillate between feeling paternal and rejecting their child as they strive to strike some kind of balance. Some parents feel guilty of their rejection and make up for it by going overboard on care provision, rushing to an early intervention and development centre, sometimes before the baby is even one month old, and desperately urging them to start stimulation as soon as possible. This first request is widespread and vague; the visit is made because of the DS diagnosis but the diagnosis does not have the same meaning for all families. It is a time when parents are extremely sensitive as they are overwhelmed by multifarious feelings. As professionals, our job is to help parents connect with their child, who at this early stage and at times later on also, is only seen through the 'lens' of the diagnosis.

Feelings related to rejection of the disability can manifest themselves as:

- Grief for the loss of the ideal child
- A sense of incompetence: the parents may feel that their ability to reproduce is under question, which can dent their self-esteem
- Uncertainty linked to a lack of knowledge or

misconceptions about DS

- Anger and hostility
- Confusion

So, when a baby is born with a disability, the bond that has been forged thus far, the relational encounter, is broken. Letting go of that expected ideal baby and coming to terms with the reality of a child with a disability triggers the grieving process – a long but necessary process for creating a new internal space for the baby that *has* been born. Gradually, the parents will be able to get to grips with this traumatic reality and want to be parents to their child. Reconstructing the initial bond must not only involve a gradual acceptance of this reality (being the parents of a child with a disability) but also fundamentally of the fact that, first and foremost, that child is a PERSON

Like any other, a child with DS is a person who will develop and construct their subjective self thanks to their relationship with the Other. However, in this process of becoming an individual, the child with DS will additionally have to construct their subjective self as a person with DS.

We shall now examine some of the most specific factors that in our experience have a bearing on the psychological development of children with DS.

### Relationship imbalances

As was discussed in the first part of this article, organisation of the psyche is underpinned by the relationship bond, and it is this that allows the child to get to know, understand and adapt to the world around her.

Certain constitutional characteristics in children with DS (such as intellectual disability and hypotonia) may result in these babies having a low level of activity initiation and physiological sensitivity and therefore taking longer to assess situations and process information. Consequently they are often slower to respond, which can be interpreted as failing to react. Such an interpretation can:

- thwart the early bonding process
- prevent the Other from developing trust in the child because non-response feels awkward and the Other jumps in
- mean that the strange, the unknown (DS) is met with rejection, thereby hampering the bond

Therefore, in the case of the child with DS, an intellectual disability can be perceived as a shortcoming in the subjective self, which means that the child is no longer seen as an autonomous subject but as an object of care. This may bring about ‘relationship imbalances’ that are often at the heart of problems when the child’s behaviour and intentions are interpreted in her social setting (by parents, relatives, friends, professionals and so forth). It is not unusual to see people judging the behaviour of a child with DS as disconnected from her internal processes (taking it at face value), or putting these manifestations down to the syndrome.

The primary goal of early intervention is to enhance the relationship that the child has with her parents, which at this initial stage of confusion, anxiety, questions, concern and so on, may be very precarious. Elsa Coriat (4) believes that babies with DS have the same needs as any other baby. However, this is problematic not only because of the narcissistic wound that brings about an abrupt loss of all identification signals, but also because the baby is less innately equipped to stimulate her mother, who may seek to fill this void by turning to methods, techniques and specialists. The stance that the professional takes on this is vital, as it can either help or harm the bond between mother and baby.

### Unconscious erasure of paternal functions (and other social roles)

It is also common to find what can be described as an ‘unconscious erasure of ability to parent, grandparent, teach, and so on’ by experienced parents or teachers, because they struggle to recognise that the child with DS does have certain capacities and her development is not therefore solely contingent upon the adult. This can be compounded by fear of the unknown, which feeds these unconscious defence or erasure mechanisms.

When a child with DS finds she has the space and time to emerge, however, she brings about what we might call the ‘surprise factor’ in her parents, relatives and professionals who had little expectation of her because, as discussed above, the intellectual disability means that the child is seen as an object of care rather than an autonomous subject.

Therefore, we believe that professional intervention must seek on the one hand to help

parents understand their child's reality, adapting to her emotional and experiential needs, and on the other, to enhance their skills as parents.

### Avoiding frustration

This reluctance to see a person with DS as an autonomous subject brings us to another aspect which to a greater or lesser extent can come into play as the person grows and matures: parents (or professionals) avoiding conflict situations and the subsequent difficulty for the person with DS in coping with frustration.

Today's society is giving rise to an alarming paradox: on the one hand we are increasingly aware of the rights of the child, and on the other we are also seeing a progressive loss of parental authority. If we are already struggling to prepare children without disabilities to handle frustration (putting limits on children is a major issue and there is a disproportionate tendency to 'fill' children with desires), what hope is there of personal growth in children with a disability? Few people believe that frustration is part and parcel of growing up. Because growth (becoming an individual) in children with DS is fraught with concern, very frequently they are shielded from all conflict, and without frustration there is no growth. To see this we have only to look at what parents say when they are asked what they would like for their child with DS: "I want her to be happy". Avoiding all conflict is not leading a normal life, because growth of any kind involves difficulties and frustration.

### Action as a means of expression

Due to the intellectual disability in children with DS, thought and reasoning abilities are slower to develop.

Because of this shortfall in symbolic resources, the child with DS often displays disturbing behaviour in situations of stress or disorientation,

or when seeking attention (e.g., violence, flight behaviour, not asking the adult, not relating to other children, etc.) as they simply have no other way of getting their message across. It is therefore important to observe, consider and attempt to understand what is at the heart of such behaviour – what is the child trying to tell us?

### Acknowledging the disability in constructing one's identity

We would like to conclude this paper on psychological factors in the development of children with DS by underscoring the importance of the person with DS being able to construct their identity as a subject with DS. Coming to acknowledge and accept the disability and seeing that even amongst people with DS everyone is different must enable the person to construct their identity. Having discovered their identity the person will be better equipped to integrate into society in acceptance of their own reality, with their limitations but also with awareness of their own potential and a true Self.

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