

## Lost in transitions

### 1 Introduction

Do you remember the movie *Lost in Translation*? Bob Harris experienced a midlife crisis, traveled to Tokyo, met Charlotte. Their world needs to be refined; they have questions; they feel unsure about the future. On top of all this, they met in Tokyo – and the culture shock was a fact.

This is what happens when parents of a child with life-long needs meet the culture in childcare and then in school. From now on we will call the child “Oleane”. They can get lost in transitions as they feel a deep insecurity. They are unable to understand and they do not feel understood. Poor translations can never evolve into good enough transitions.

We will look further into the way the education system around parents can develop and use tools so that parents have a real feeling of participating in their child’s transition from home to childcare, and from childcare to school. They need to have a sense of security when sending their child out of their nurturing home.

This contribution is written based on my experience from many meetings with parents in Norway and in the Norwegian education system. Here, we considered childcare and school equally in terms of education arenas with similar needs when they welcome children like Oleane.

There are numerous transitions in life. From hospital to home, from home to childcare, from childcare to school and different school levels, from school to a sheltered home (for children). I have chosen to write about transitions in early intervention (zero to seven years). In any case, despite the many different systems listed above, the concerns and implemented measures for the different transitions are similar in regard to children with severe multiple disabilities.

So, who are the children we want to present here?

### 2 Oleane

McCormack (2017) chooses the definition of Bellamy et al. (2010, p. 233) to describe people with PMLD.

- People with Profound and Multiple Learning Disability (PMLD):
- Have extremely delayed intellectual and social functioning
- May have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch and gestures)
- Often require those who are familiar with them to interpret their communication intent
- Frequently have an associated medical condition, which may include neurological problems, and physical or sensory impairments.

They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualized relationship with a carer.”

Oleane is part of a very small group of children at the lowest level of functioning. They express themselves essentially through body language. Shoshana Dreyfus (2020, p. 25) describes her son Bodhi like this: “Our lovely, lively non-verbal but highly communicative son”. We think many parents can recognize their child in Shoshana’s description.

They have a number of health problems and therefore must endure many hospitalizations. The children also experience pain, causing them to persistently readjust their body position, which leads to a loss of focus. They are very dependent on technology and their caregivers, who must make every effort to understand what they are trying to convey (Heimdahl & Serrano, 2020).

These children are identified differently, depending on various services through which they receive help. PMID (Profound Multiple Disabilities and Intellectual Disabilities), PIMD (Profound Intellectual and Multiple Disabilities) PMLD (Profound and Multiple Learning Disabilities) to name a few. There are differences between countries, too. For instance, it is more common in the UK to speak about PMLD, whereas PIMD is used in Australia. In Italian and French, they use the word “plurihandicappe”. In the Norwegian education system, we use the term “Multifunksjonshemming”. Despite many “labels”, the children have names, their own names.

A label does not define Oleane; it rather indicates that Oleane experiences barriers to learning and participation. She cannot describe that by herself. Methods are required that can safeguard her voice and bring it further through all transitions.

### 3 Parents’ concerns in transitions

A transition means changes and unpredictability, which in turn leads to concerns. This is the case for all parents who open the door at home and send their child out in the world. In any case, for Oleane’s parents, the transition is more stressful than for parents of average developing children.

Frequently, already in the first days in the hospital, the parents are told that their child probably will not live very long. However, day after day, their child survives against all odds. There is a feeling that life stops – and at the same time life goes on.

The fear of sudden death does not disappear. The parents live in what is described as “anticipatory grief” (Grasaasen, 2020). Imagine if the child were to die when mommy and daddy are not there; they are left behind with questions; Did their child suffer? How did the people around act?

How difficult is it to talk with “new” people, to identify the feeling of waiting for something terrible to happen, to say the word death? Different parents experience different fears. The goal of parents is to do everything in their power to give their children the best life they can, even if that life is not very long.

As explained above, all these concerns contribute to the fact that Oleana’s transition is more stressful than that of other children.

Lazarus and Folkman (1984), in the transactional model of stress and coping, states that stress is a condition or feeling experienced when a person perceives that the “demands exceed the personal and social resources the individual is able to mobilize”. They define psychological stress as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing. In the experienced transitions, there are many feelings of how things will mobilize.

The concerns are related to the fact that new professionals do not know the child, Oleana’s way to communicate, her health problems. What do they know about AAC (Alternative Augmentative Communication)? How is the rhythm of the day, how is the physical and learning environment? Is there enough space for equipment and technical devices? Who can help to inform about diagnoses and Oleana’s specific needs? Do they need support from others they have met, such as the hospital, Children’s Habilitation Center (HABU), service providers such as special needs teachers and nurses, National Agency of Special Needs Education (Statped)? The parents wondered if other children would want to play with her. What kind of play could she engage in while in a wheelchair and her hands mostly in her lap? Will Oleana be isolated and alone? Will too much noise frighten her? On the other hand, it is sad to imagine Oleana in a very sheltered environment, quiet but perhaps alone and lonely. All these questions demand answers. All these worries demand to be identified.

To cope with the experienced stress, parents need the professionals to find and offer answers to the endless list of questions, and to do it *with* them. In what Lazarus and Folkman (1984) defined as a primary appraisal, the parents find out that “yes, it is stressful”. Secondary appraisals involve the feelings related to dealing with the stresses. Lazarus and Folkman would say they feel that the professionals build the “new world” on the basis of the “old world”. Oleana’s story will follow her. She does not need to start from the beginning, to enter this new place as a *tabula rasa*.

This is the best coping strategy to meet parents in the complex world of transitions, where they need comprehensive translations of the kind of worlds childcare/schools represent, how they can meet the child’s needs and what they have to prepare for in advance. Ultimately, the parents must have a genuine feeling that they participate as equal partners, that they can tell who the child is, that it is their child who travels onward in life.

#### 4 Professionals’ tools to meet parents’ concerns

Try to put yourself in Oleana’s shoes. Places change; the smell of a new environment, the echo in the rooms, new voices, new sensory impressions when the wheelchair rolls along the path to the door, new ways to be touched, to be moved, to be surrounded by other children. However, Oleana’s basic needs are almost the same. Despite differing education systems, the needs of children like Oleana are similar over their lifespan.

This concerns an appropriate use of equipment, a need for health services, a daily rhythm with sufficient quiet/calm, sensorimotor activities, a sense of security, and a limited number of different professionals handling their body.

Potential barriers could be administrative ones – concerning ratios, having enough time for coworking, taking part in planning, orientation visits, workshops and so on. Other issues can involve family concerns that have not been addressed, or worries about shifts in approaches, for instance from a play to a curriculum-based approach. I will present two tools we experienced as helpful in transitions for children like Oleana. The first one is a communication book, a kind of “travel passport from one country to another”. The other one is a list designed to help in remembering all the details that are important for successful transition.

#### 5 A passport to cross the borders: Me-My story

The biography of Oleana is often very fragmented. There have been many storytellers during her few years of life: close caregivers, medical staff, professionals in early childhood education, physiotherapists and occupational therapists, speech pathologists, vision and hearing specialists, social workers. And this is just a few of the practitioners who have met Oleana. Everyone has a story to tell from their own perspective. How can we guarantee that Oleana gets to use her own voice?

Me-My story is a tool to ensure that the whole of Oleana travels confidently to the next arena. McCormack (2017) points out that ethnographic methodology is a good starting point for being within the microworld of people with PMLD. She refers to the methodology applied in collecting life stories. Atkinson (2010, p. 7) quoted in McCormack (2017) writes: “Life stories, and the opportunity to tell them, are particularly important for people with learning disabilities because they have often been silent, or silenced, while other people – families, practitioners, historians – have spoken on their behalf. Life stories begin to redress that balance as they become a means by which people with learning disabilities have a voice that is theirs”.

This is the only way Oleana can tell the world about herself. We have experienced that this kind of communication book is needed for Oleana to tell who she is and what she needs. The form to be used is I-form. Not even the people closest to Oleana can read her easily; something unusual and unexpected can make the readability of Oleana challenging.

My storybook will present Oleane in different aspects of everyday life, describe how people around her best can interact, which expressions are special for Oleane, which particular rhythm of the day suits her, which activities she prefers. A pictorial book containing Oleane's pictures of interaction moments, short comments and explanations, her vocal expressions, tactile signs and preferred activities, and her ways of participating. In a communication book, tiny signals can be translated into a richer description. Oleane's idiosyncratic language will become more explicit and understandable for new people around her.

An approach for understanding more of Oleane's world and signals is to build up a network together with close caregivers and professionals. This is a pedagogical tool. Close caregivers and professionals work together and share stories. In that way they establish common ground through video analysis, assessment and measures/goals which are worked out together (Heimdahl & Serrano, 2020).

Another good approach to create common ground is Peter Limbrick's (2009) TAC (Team Around the Child). This way of thinking makes it possible to develop tools that unite the people around Oleane and give her a voice. Limbrick describes TAC like a team that sees all aspects of the child, sees the child within the bigger systems of close and wider family and community, sees each child's impairments and disabilities as interconnected parts of an emergent, unique and multifaceted condition, brings together the people closely involved into a whole intervention system around the child and family, and integrates, as appropriate, separate treatments, therapies and educational programs into a holistic approach.

Me-My Story must be written day-by-day. This could represent the passport she needs for crossing various borders in her life. She needs this kind of passport on her travels through the education system, but also in her hospitalizations, or as part of the album for grandma and grandpa who do not meet Oleane so often. The book will be like a passport that helps Oleane be recognized and valued without re-starting on a blank sheet again and again.

## 6 A list to remember

Another tool is a list to remember. It takes time to write a list. An assessment of the different places takes time, as does an overview of the human resources involved. It is important to schedule transition planning meetings at an early stage. Regular, ongoing evaluation meetings are also important. Oleane has complex needs and a great deal of equipment. We have experienced that it is wise to start the transition planning at least one year in advance.

### 6.1 Parents' expectations

It is a good idea, during an initial meeting with Oleane's parents, to listen and allow them to ask about "everything" they need to ask about. There are no silly ques-

tions. They can present a snapshot of their child. Despite how many reports the professional has read, do not end the meeting without letting the parents speak, in their own words, about:

- What Oleane likes and dislikes
- Which activities and persons she experiences at home
- How to know Oleane is becoming stressed
- How Oleane learns best by visuals, by tactiles
- The rhythm of her day
- The different "corners of her worlds"

Ask what kind of expectations they have of the "country" they are travelling to – to childcare, to school? The first meeting is of vital importance. This is where the professional's attitudes interface with parents' awareness of what kind of place Oleane is travelling to.

### 6.2 Professionals' commitment

Professionals must have the opportunity to visit the childcare/school. This is important for parents; however, it should also be of importance for the new professionals in Oleane's next arena. At this point, the methods used, and equipment must travel alongside Oleane.

This applies to all knowledge about body language, the use of keywords and signs, and the use of visuals and communication boards. Also, physical, gestural, and verbal prompts, preferred songs, music, and toys. Particularly when the child cannot tell his/her own story, it is important that there is a sense of coherence and recognition between places. The "luggage" travels with the child and must not be left behind. It is important from the beginning to meet key people who will spend time with Oleane – not merely people from administration. We experienced that this can be difficult, as employment plans for the coming year are frequently not ready in advance. In any case, this is a good secondary appraisal for parents going through the planning of stressful travel.

This is intimately interwoven with another question: How is the ratio of child to adult? How many persons will care for my child? There is a desire to know more about the professional's competencies and strengths. What is needed to extend and improve existing knowledge and insight? The parents want kind, engaged and nurturing but qualified professionals, too. The professionals, on their side, want to build a good relationship with the parents for the benefit of the child.

### 6.3 Empowering each other

Planning of lectures and workshops on communication, adaptation and facilitation is important. Sometimes it is more useful to exchange experiences among partners than to hold a traditional lecture from expert to receiver. One could say that listening to

each other's stories has a huge impact when it comes to feeling genuine participation in transitions.  
Getting to know Oleanne does not mean starting from scratch, rather making use of what those before us have discovered.

#### 6.4 New everyday life

There are many questions about new locations. How is the new arena in regard to the physical and learning environment? How is the lighting? What does the visual and auditory environment look like? How is toileting adapted to the child's needs? Is there enough space for all the different equipment? Is there sufficient storage space? Because of Oleanne's health needs, it is important to note down an emergency plan in case something where to happen. Who are the emergency contacts that the child-care/school can call and in which order? What to do if she has a seizure? What to do in the event of suffocation/choking?

The need for information flow from childcare/school to home is yet another important topic. The need for information is unending. It is useful to agree about use of a diary, a digital contact book (Book Creator on an iPad), evaluation meetings, held physically or digitally.

#### 6.5 Oleanne meets other children

We need to identify any other professionals that parents and children in the new arena have use for. The parents' approach to the disability, their network, the attitude in the neighborhood varies somewhat; we have met parents who want to come to school and talk to other parents; however, we have met other parents who have delegated the task to the professionals.

Oleanne is not just the special educator's child. All the professionals and the children in the new arena must be informed on how to meet Oleanne in an appropriate way. A good idea is to arrange a play day in advance with a range of sensory activities, involvement in daily routines, organize picnics, or a moment of calm in a quiet corner. This will teach the other children how to greet and play with Oleanne in everyday activities. An example might be how to handle her wheelchair. They will recognize that there are different ways to eat, because Oleanne eats through a feeding tube. This is just to mention a few-inclusion aspects.

The other children ask questions, and it is our responsibility to give them answers. They are satisfied when they hear that Oleanne sits in the wheelchair because she cannot walk. Benjamin was very quick in his conclusion: "Then she cannot run either. But can I drive her faster?" There is a huge potential to give information through everyday activities.

#### 6.6 Summary table

A table like the one below can summarize the different points to remember and can function as a template to follow during various meetings.

What to do	Who is responsible?	When
Visit each other: <ul style="list-style-type: none"> <li>Parent to child-care/school</li> <li>Professional from the childcare to home</li> <li>Professional from school to childcare</li> </ul>		
Information about the child		
Information about diagnoses		
Workshop, collect and share stories, show video clips		
Emergency plan		
Who will work with the child, and their qualifications		
Physical environment		
Learning environment		
Equipment and educational materials following the child		
Information to parents		
Information to others		
Evaluation meeting		

Table 1: Summary table

## 7 Conclusions

There are no universal answers or models. There is a child who must be welcomed in the best possible way into the childcare or to the school. It is about acknowledging the perspectives of others and to work further on partnerships from the very first moment.

We remember parents who said: "We feel welcomed". They are happy to have Oleane in her group. We think these are the best words to define what a successful transition means.

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Simone Kannengieser

## Am Übergang zur Mehrsprachigkeit

Der Übergang von der familiären Lebensumgebung zum Besuch der ersten Betreuungsinstitution kann für Kinder ein sprachbiographischer Wendepunkt sein.

Der folgende Beitrag geht von einer alltäglichen Mimikze aus und endet bei einer bildlichen Gegenüberstellung von Haltungen, mit denen sich Fachpersonen Kindern und deren Familien nähern und in Beziehung treten. Der Übergang in die außerfamiliale Betreuung wird somit unter den Aspekten von sprachlicher Erziehung sowie von pädagogischer Beziehungsgestaltung beleuchtet.

Durch einen reglementierenden Umgang mit Sprachen wird nicht nur die (Nicht-)Erwünschtheit einer gewählten Sprache markiert, sondern es werden Bedingungen sozialen Ein- oder Ausschlusses transportiert und Selbstbilder der Kinder tangiert. Am Übergang zur Mehrsprachigkeit kommt der unbedingten Anerkennung des Erstsprachgebrauchs eine große Bedeutung zu.

### 1 Beschreibung einer alltäglichen Szene

Eine Fachperson führt mit einer kleinen Gruppe von Kindern eine Übungsaktivität für die Wortschatzförderung durch. Es werden Bildkarten mit Obstsorten aufgedeckt. Die Aufgabe der Kinder besteht darin, die Bilder zu benennen und zur jeweiligen Obstfarbe ein gleichfarbiges Chiffontuch aus einem Korb zu wählen. Ein Mädchen, dessen Familiensprache Italienisch ist, deckt das Bild mit Zitronen auf. Die Fachperson initiiert die Benennung, indem sie das Mädchen fragt, ob sie wisse, was das Abgebildete sei. Das Mädchen beantwortet diese Frage mit der italienischsprachigen Bezeichnung. Die Fachperson reagiert mit einer Rückfrage: „Wie?“, woraufhin das Kind seine Antwort wiederholt. Daraufhin artikuliert die Fachperson den Initiallaut der deutschsprachigen Bezeichnung, wiederholt den Laut, und spricht die Bezeichnung betont vor. Daraufhin kommt das Kind erneut der Benennaufforderung nach und verwendet jetzt das vorgeschriebene deutsche Wort. Die Fachperson bestätigt und „genehmigt“ diese Antwort nicht nur, sondern spricht ein ausdrückliches Lob aus.