Children with Severe, Multiple Disabilities: Interplaying Beings, Communicative Becomings

Kristin Vindhol Evensen

Abstract

According to the United Nations Convention on the Rights of the Child, being understood is a human right. This chapter focuses on children with severe, multiple disabilities and their transitions between interplay and communication, between embodiment and expressive skills, between subjectivity and objectivity, between expressivity and interpretation, and between being and becoming.

Through a literature review, I show that transitions between interplay and communication when children have severe, multiple disabilities are considered from three dominant perspectives.

Papers that describe communication as an objective technique describe technical possibilities when translating highly subjective expressions of children with severe and multiple disabilities into symbolic language. However, critical self-reviews by the authors of some of these papers indicate that their findings show that those technical communication skills are of restricted value if the relation between interplay and communication remains unproblematised.

Papers that describe the children's communication as a result of contextual impressions, and relational and interactional stimuli show that neither disability, nor the context alone can shape the child's potential abilities, or his or her wish to enter into interplay or to communicate. On the contrary, it seems that the quality of interplay that the participating children are *already* taking part in appears to be decisive when the children express their experiences to the people surrounding them.

Papers that describe expressions as causally connected to diagnostic phenotypes describe important objective features of medical diagnoses, yet, it appears that possibilities for interactions and communication are lost when movements are interpreted as results of medical conditions rather than as subjective expressions.

Keywords

children with severe – multiple disabilities – interplay – communication

1 Introduction

To be understood is a human right, also when symbolic communication is challenged. The United Nations Convention on the Rights of the Child (1989) states that no child shall experience discrimination because of their disability. In addition, the convention includes two articles that are specifically directed towards the right to freedom of opinion and expression. Article 12 (1) of the above Convention describes how states should assure that children who are capable of forming their own views have the right to express their views. In addition, this article states that these expressions shall be given the appropriate weighting in conformance with the child's age and maturity. In article 13 (1) of the Convention, the United Nations enhance that freedom of expression by including expressions that exceed verbal and symbolic expressions, in a spectrum including speech, artistic expressions or expressions of the child's own choice. Thus, being accredited as expressional is the right of every child, including children with severe, multiple disabilities. Skarstad (2018) demarcates the importance of accrediting persons with intellectual disabilities as expressive from a human rights perspective. She refers to the United Nations Convention on the Rights of Persons with Disabilities to pinpoint the importance of acknowledging interests, personality and lived experiences as keys to different kinds of expressiveness when intellectual disabilities make symbolic communication difficult.

Children with severe, multiple disabilities are typically subject to extensive use of technical assistive devices such as wheelchairs, standing and walking aids and orthoses. When a person experiences an application of external forces that limits freedom of movement, he or she is 'automatically forced from the circle of the proper' (Goffman, 2008, p. 93). When assistive aids, bows, Velcros and straps apply external forces that limit a person's freedom of movement and co-exist with internal forces such as intellectual disabilities, spasticity, epilepsy and loss of senses, children with severe, multiple disabilities might experience limitations in their possibilities to express their perspectives (Evensen, Ytterhus, & Standal, 2017; Hautaniemi, 2004; Horgen, 2006).

This chapter specifically focuses on how research describes children with severe, multiple disabilities as they move between non-intentional interplay

and interpretive, intentional communication, between subjectivity and objectivity, between embodiment and skills, and between being and becoming, all against the backdrop of the phenomenology of perception as understood by Merleau-Ponty (2014).

2 Interplay and Communication

The German philosopher Habermas (as cited in Lorentzen, 2009) emphasises that the communicative human being intentionally wants to pass on a message. The task of those that communicate with each other is to explore a partner's ability for intentional communication, and thus to adapt to the attributes the other has at hand. Hence, communication will always include more than one person. For an expression to be detected, interpreted and included in further communication, the communication partner must also have the intention to communicate and must have sensing, looking, listening, feeling and smelling attributes to pay sensitive attention to what is uttered or gestured (Fröhlich, 1995; Horgen, 2006). When humans express their perspectives, listen to others and adapt to their communication partners, each person receives stimulation to communicate his or her perspectives in ways that do not depend on a shared symbolical language. Through intentional expressions and intentional sensing, communication turns dialogical, sequential and directed from the past, through the present towards the future (Toombs, 2001).

Intentionality is what makes a distinction between communication and interplay. The interplaying human is released from intentions and strategies. Being together and getting to know the perspective of each other is a goal by its own means, where I have to be open to getting to know your perspective in the same way as you have to be open to getting to know mine. This means that both of us have to give ourselves up in partly unpredictable situations because your perspective will always be different from mine and mine will be different from yours. These subjective perspectives can be – but are not necessarily – carried out through a shared, objective and intentional symbolic way of communicating. Thus, interplay will always have an uncertain outcome.

Being in interplay provides shared experiences. The French philosopher Merleau-Ponty (2014) describes how he, Maurice, and his friend Paul share the same focus, yet he acknowledges that they are two different persons, having two different points of departure. Still, they are connected through a shared experience. Maurice and Paul share details in a landscape when Paul points his finger towards a steeple. Maurice and Paul do not perceive the steeple from the same point of view. However, from that moment of shared attention, they

share an experience and a story of a steeple in a landscape. Such stories of shared attention bridge different points of departure in human experience.

The non-strategical and unpredictable nature of interplay and shared attention is closely connected to the openness of play. Karoff (2013) describes how play takes place between play practices and play moods. To be in a play mood is to be open and ready for the possibilities of other persons producing meaning. Through layered reciprocal interplay, the ones in play are surrounded by a certain uncertainty depending on who is taking the next step. The players will experience reciprocal unpredictability when intensity changes the rhythm of interplay. The players will experience reciprocal shifts of tension, where they show who they are while being aware that they are being looked at by the other. Lastly, the players might experience euphoria caused by the possibility of their own and others' silliness, a silliness released when the illusion of controlling the situation is terminated (Karoff, 2013).

Through layering, changes of intensity, shifts of tension and possibilities of silliness, humans can harmonise with others in play practices. Play practices are actions undertaken when being in a play mood. Play moods are not instrumental, intentional or purposeful in the same way as play practices are. Play practices are play moods expressed through actions. In play practices, the playing humans express their moods through behaviours, the use of toys and objects and through the ways they move their bodies, all with an intention of sustaining the play. Thus, we can understand play moods to create the foundation of play practices in the same way as different subjects' shared interplay is foundational for communication to take place.

3 Children with Severe, Multiple Disabilities: Perspectives

Because of the complexity and severity of their diagnoses, limiting possibilities for symbolic communication and creating a need for other ways to understand and be understood, children with severe, multiple disabilities magnify the layered appearance of interplay and symbolic communication. The literature understands and describes the limitations and possibilities of children with severe, multiple disabilities in a wide range of perspectives.

From a medical, diagnostic perspective, severe multiple disabilities are understood as complex conditions where intellectual disabilities are combined with motor-, somatic- and health-related difficulties, and in some cases loss of senses such as sight or hearing.

From a socio-relational perspective, the complexity of conditions results in difficulties caused by mismatches between persons with severe, multiple

disabilities and their socio-cultural environment. Continuous assessments of individual hallmarks, medical needs and social environments such as homes, kindergartens and schools, create frameworks for adaptations where significant other possibilities are sought to align the mismatch to a greater or lesser degree.

From a phenomenological perspective, persons with severe, multiple disabilities are considered to have subjective interests, different meanings and different social and experiential backgrounds. In this perspective, children with severe, multiple disabilities are acknowledged as full-worthy active and perceiving children who, when moving in space, in time with objects and in relations with other persons, live experiences with the same values as everyone else.

4 Children with Severe, Multiple Disabilities: Perceptual Phenomenology Challenges Normality

To find a relationship between medical knowledge, social expectations and phenomenological embodiment, I follow French philosopher Merleau-Ponty (2010, 2014) in examples where normality is challenged. Investigating expressiveness from a phenomenological perspective provides a possibility to overcome the dichotomy of being able or disabled, as it unfolds in medical and social perspectives. However, I make a sociological “Goffman” (2008) turn by including children who are severely limited in their embodied freedom to investigate interplay and communication. Goffman included persons who experienced internal or external embodied constraints into his research to investigate possibilities of general human relations. To explore how acknowledging various ways of expressiveness can be formative for a person’s possibilities to be understood, I turned to an outpost of symbolic communication. Thus, children with severe, multiple disabilities, whose performance of symbolic language is either out of reach or requires thorough training, are main contributors to this investigation.

Interactions, whether through interplay or symbolic communication, are easily shaped by the asymmetry between interactional partners. I will argue that asymmetry contains possibilities to accredit and include embodied expressions of humans with severe, multiple disabilities into interplay in ways that create meaning for the parties involved. This approach is challenged by the phenomenology of perception. In the philosophy of Merleau-Ponty (2014), a whole world can be expressed when gestures, sounds, mimicry, body position, change of breathing or the gaze of an eye, are acknowledged as

full-worthy expressions and are included in further interactions. Thus, I claim that accreditation of embodied expressivity is a path towards a balanced meeting that bridges gaps, even when relations are asymmetrical due to different persons' points of departure.

Interactions in pre-symbolic life are often carried out as highly asymmetrical and hierarchic, where values are communicated from the adult to the child. Hence, hierarchy is sustained when values are transferred from the person communicating symbolically to the person communicating pre-symbolically, to lead the latter to a more complex and credible level of communication. Merleau-Ponty held a position as chair of psychology and pedagogy at the University of Sorbonne from 1949 to 1952. In 'Child Psychology and Pedagogy. The Sorbonne Lectures 1949–1952' (2010), Merleau-Ponty's validation of students' notes on his lectures shows us that he criticises a pedagogical approach that leaves the child in a state of being an unfinished adult. However, Merleau-Ponty does not naively erase differences between adult and child to create an equilibrium. Even in objective discussions, Merleau-Ponty claims that it is alluring to be the one who is proved right (2010). He underlines the importance of being critically aware of the longing for being right and the asymmetry between adult and child.

... the triumph of reason is always felt as a personal triumph. Moreover, situations are rarely completely equal. Even if we make an effort to respect the autonomy of the other, even if we grant the other freedom, the other will never feel completely free since he receives his freedom in a partnership. (Merleau-Ponty, 2010, p. 83)

Merleau-Ponty also challenges the notion that the experience of disability is a state of being disabled towards a given standard of normality and ability. Thus, he dares us to consider whether having a disability includes an obligation to strive towards standards of what is considered to be able within the borders of normality:

The desire for a healthy body or the refusal of the diseased body are not formulated for themselves; the experience of the amputated arm as present or of the diseased arm as absent are not of the order of the "I think that"

This phenomenon – distorted by both physiological and psychological explanations – can nevertheless be understood from the perspective of being in the world. What refuses the mutilation or the deficiency in us is an I that is engaged in a certain physical and inter-human world, an I that

continues to tend toward its world despite deficiencies or amputations and that to this extent does not *de jure* recognize them. (Merleau-Ponty, 2014, p. 83, original emphasis)

To shed light on the possibility that humans have to acknowledge various states of being fully worthy of expressivity in a landscape between interplay and symbolic communication, I follow Merleau-Ponty's *Phenomenology of perception* (2014) and *Child Psychology and Pedagogy. The Sorbonne Lectures 1949–1952* (2010) to provide an alternative perspective that challenges the asymmetry that appears when pre-symbolic language is mainly presented as an unavoidable, mandatory transition towards future symbolic language. If we let go of the triumph of reason, asymmetrical relationships can persist above conflicts and the battle of being right is renounced (Merleau-Ponty, 2010).

5 Severe, Multiple Disabilities, Interplay and Communication in Research

In addition to Merleau-Ponty's philosophy and pedagogy, this chapter includes results from a literature overview investigating how research describes interplay and communication of children with severe, multiple disabilities. The perspectives of students with intellectual disabilities in general and students with severe, multiple disabilities in particular, are rarely subject to research, and when they are, the research approaches are either medical, social or behaviouristic (Evensen, 2018). These approaches to intellectual disabilities and movements in general, and movements of children with severe, multiple disabilities in particular, find resonance in the work of contemporary disability researchers Egilson, Ytterhus, Traustadóttir, and Berg (2015). They state that the dominant perspective in childhood disability research

is framed within special education or rehabilitation, often taking a bio-medical and individualistic approach. The dominant perspective has been medical, viewing disability as an abnormality of the individual child. There is an urgent need for an alternative to this narrow understanding of childhood disability that draws attention to and articulates the social relational views of disability which is currently considered the cornerstone of forward thinking in disability policy and which is also one of the foundations of the UNCRPD. There is also a need to develop understanding and knowledge about disabled children using social, cultural and human rights perspectives, especially research-based writings that

bring forward views and perspectives of disabled children and youth.
(2015, p. 3)

To investigate the possibilities children with severe, multiple disabilities are given to express their views, I conducted a literature review that focused on interplay, interaction and communication, separated for analytical purposes, yet with the knowledge that these features are intertwined and hardly separable in subjective lived experiences.

The review revealed three main directions in previously published research. The most prominent direction describes interplay and communication of children with severe, multiple disabilities as pure technique. The second most prominent direction describes interplay and communication as a result of contextual impressions, and relational and interactional stimuli. The least prominent direction describes interplay and communicative expressions as causally connected to diagnostic phenotypes.

When connecting research literature to phenomenology, I will emphasise that pedagogical possibilities are inherent when recognising the subjectivity of interplay and interactions and objectivity of communication as intertwined, where one cannot fulfil its potential without the other being present (Lorentzen, 2009). However, paying attention to differences between playful, non-intentional interplay and intentional communication provides important knowledge when analysing expressions in daily life situations, in pedagogical contexts as well as in academic reading and writing.

6 The Literature Overview

During February 2018, I conducted a literature overview by searching the databases Web of Science, EBSCOHost, SPORTDISCUS, ERIC and Oria. I included the concepts child*, young child*, communicat*, interact*, interplay* with severe* multiple* disabil*, and severe* multiple* impair*. The search produced a total of 454 papers. Reading headings and abstracts, I excluded papers that included humans older than 18 years of age, papers that included deaf children and children with blindness and autism spectrum disorders but without intellectual disabilities and papers that included parental communication in the supporting system.

Despite the challenges that children with severe, multiple disabilities face when expected to perform symbolic communication, the prominent research discourse has treated communication of children with severe, multiple disabilities as a skill that can be trained, as depending on contextual impressions,

relations and interplay, or as causally related to diagnostic phenotypes. The findings in the overview are thematically presented in tables with a short phrase about each paper's contribution to the findings. Then, chosen examples are presented in a more elaborated way.

7 Literature Overview Findings Presenting Communication as a Technique When Children Have Severe, Multiple Disabilities

A total of 15 studies describe *communication as trainable, technical skills*. Four out of these contain critical discussions addressing whether technical skills alone provide access to the perspective of the child.

Out of the 15 papers concerning communication as technique, there are nine intervention studies where one child or three children test one or more assistive technical communication devices. Four studies are literature studies, one is a survey including perspectives of parents and professionals, and one study is a mixed-methods case study.

The majority of these 15 studies show that children who participate increase their technical communicational competence. They learn to use switches to make choices. They learn to point out symbols representing persons they want to be with, or objects they want to play with, when they use the graphic symbolic language BLISS, or when they use other augmentative and alternative communication techniques. For example, Lancioni, Singh, O'Reilly, and Bacani (2006) describe how the participating children learn to push switches that transform their subjective expressions when providing an affirmative response saying 'yes' – such as lifting the foot, and a negative response saying 'no' when turning the head – into symbolic language where their affirmative and negative responses are translated and spoken verbally by a canned voice machine.

Altogether, these 15 papers describe a large potential when it comes to translating subjective expressions of children with severe, multiple disabilities into symbolic language, thus making the expressions of the participating children more easily accessible for others who do not know their subjective expressions, wishes and needs. Meanwhile, critical studies show that technical communication skills are of restricted value if the relation between interplay and communication remains unproblematised. Suhonen, Nislin, Alijoki, and Sajaniemi (2015) give an example when they describe how children with severe, multiple disabilities do not necessarily increase their social competence even if they increase their technical communication skills. The children tend to fall outside play as a social field, even when they have developed technical communicational skills directed towards play participation. The children that acquired

TABLE 4.1 Communication as technique

Papers	Theme
Calculator, R. (2009)	Interventions involving the use of augmentative and alternative communication (AAC)
Campbell, P. H., Milbourne, S., Dugan, L. M., and Wilcox, J. M. (2006)	Assistive technology, switch-activation, computer use, AAC
Horn, E. and Kang, J. (2012)	Identification of each child's needs to provide the right AAC; critical discussion
Hummels, C., van der Helm, A., Hen-Gevel, B., Luxen, R., Voort, R., Van Balkom, H., and De Moor, J. (2007)	Development of an interactive and adaptive educational toy to stimulate language and communicative skills
Lancioni, G., O'Reilly, M., Singh, N., Oliva, D., Marziani, M., and Groeneweg J. (2002)	Assessment of microswitches versus interaction to receive benefits
Lancioni, G., Singh, N., O'Reilly, M., and Oliva, D. (2004)	Use of microswitches to choose an event
Lancioni, G., Singh, N., O'Reilly, M., Oliva, D., Monitroni, G., and Chierchie, S. (2004)	Use of a chin-controlled microswitch to provide a pleasant stimulation
Lancioni, G., Singh, N. O'Reilly, M., and Bacani, S. (2006)	Use of a microswitch to establish 'yes' and 'no' responses
Lancioni, G. Singh, N., and O'Reilly, M. (2017)	Use of a microswitch to choose activities
Mumford, L., Lam, R., Wright, V., and Chau, T. (2014)	Implementation of access technologies and response efficiency
Pilesjö, M. S. and Norèn, N. (2017)	Use of BLISS to create sequences of communication; critical discussion
Shull, J., Deitz, J., Billingsley, F., Wendel, S., and Kartin, D. (2004)	Adaptation of switch-operated devices on self-initiated behaviours
Stasolla, F., Caffo, A. O., and Damiani, R. (2015)	Assistive technology use to promote communication and leisure opportunities
Suhonen, E., Nislin, M., Alijoki, A., and Sajaniemi, N. (2015)	Communication abilities in playing in Finnish kindergarten; critical discussion
Wilder, J., Magnusson, L., and Hanson, E. (2015)	Blended learning networks to share knowledge of AAC; critical discussion

new communication skills appeared to withdraw from solitary play, social play, and rough and tumble play. These withdrawals entailed that they had fewer possible experiences with formative turn-taking, problem-solving, negotiating of perspectives and use of language adapted to the present situation than they had before the skill-focused communication rehearsal was implemented. Hence, it appears that their restricted possibilities to participate in play rest upon a lack of possible interplay founded on their premises, rather than on an apparent lack of communicative competence. Further, Suhonen et al. (2015) underline that it is of crucial importance that children with severe, multiple disabilities are subject to positive experiences regarding the social aspects of communication, such as social directedness towards others and non-symbolic expressions. To attend to these values, the authors underline the importance of adults who are sensitive and responsive towards the subjective expressions of the child by imitating the child's own expressions, by stimulating emergent symbolic expressions and by supporting the child's regulation of affections.

When turning back towards the distinction between the playful mood of interplay and the intentionality of symbolic communication, it appears that interplay is supported by personal traits rather than by skills, while communication to a larger degree is objective and accessible on a symbolic level. It is nevertheless of importance to recognise that there are uninterrupted transitions between what is considered interplay and what is considered communication. However, with an operationalisation and pedagogical awareness that makes it possible to detect what divides these two features, interplay and communication will be possible to detect, acknowledge and treat separately in analytical processes, aiming for both to stand out and co-exist in a variety of life-worlds. If so, both concepts are to be understood on their own premises, ensuring that one is not judged by the traits of the other.

8 Contextual Impressions as Substantive for Subjective Expressions When Children Have Severe, Multiple Disabilities

A total of 12 studies describe contextual impressions, relations and interplay as decisive for the children's possibilities to express themselves and thus to be understood. Three of these studies accredit subjective expressions of the children, whereas four focus on intersubjectivity. The studies include video observations, interventions, interviews with the child's significant others, literature reviews and mixed methods.

Altogether, the studies shed light on contextual impressions, relations and interplay as substantive for the expressions of the child. These studies show

TABLE 4.2 Communication as contextual impressions

Papers	Theme
Groark, C. J., Muhamedrahimov, R. J., Palmov, O. I., Nikiforova, N. V., and McCall, R. B. (2005)	Interventions to promote relationships and attachment between caregivers and children in Russian orphanages; intersubjectivity
Hautaniemi, B. (2004)	Describes how children relate emotionally to the world; subjective expressions
Lima, M., Silva, K., Amaral, I., Magalhaes, A., and de Sousa, L. (2013)	Assessing responsiveness to sensory stimuli
McFerran, K. S. and Shoemark, H. (2013)	The possibilities of relations in music therapy
Munde, V. S., Vlaskamp, C., Maes, B., and Ruijsenaars, A. J. (2014)	Assessment of stimuli and patterns of alertness
Nijs, S., Vlaskamp, C., and Maes, B. (2016)	Peer interaction and scaffolding of support workers; intersubjectivity
Olsson, C. (2006)	Use of communication and communicational partners; intersubjectivity
Perifano, A. and Scelles, R. (2015)	Identification of psychological distress; subjective expressions
Stensæth, K. (2013)	Investigation of net-based musical devices with multimedia capacities; intersubjectivity
Tunson, J. and Chandler, C. (2010)	Behavioural states in a multisensory environment
Young, H. (2016)	Experiences of loss
Wilder, J. and Granlund, M. (2003)	Existing interaction patterns as a foundation for planning communicative interventions; subjective expressions

that neither disability alone, nor the context alone shape the child's possibilities or wish to enter interplay or to communicate. On the contrary, it seems that the quality of interplay that the participating children already participate in appears to be decisive as to whether the children express their experiences to the people surrounding them. For example, Groark, Muhamedrahimov, Palmov, Nikiforova, and McCall (2005) describe how Russian orphanage

children with severe disabilities increased their regulation of effects, and improved their language development, motor and social skills to a larger degree than children with minor disabilities, when the orphanage staff members were educated in how to give responsive, sensitive care. In addition, Wilder and Granlund (2003) describe the possibilities of children with severe, multiple disabilities to express their experiences as more closely connected to the caregiver's experience of the child as interplaying than to the child's objective communicative skills. Interplay thus appears to be foundational for the development of symbolic language.

Nijs, Vlaskamp, and Maes (2016) investigated interactions in adult-child relations as well as in child-child relations when the child had severe, multiple disabilities. They found that the children related to a significantly smaller degree to other children when an adult was present in the room. Using video observations, the researchers found that the children looked at each other more frequently, had a more active mimicry, increased use of voice and more frequent use of touch when alone in the child-child scenario than when there was an adult present. The only type of engagement that happened more frequently between children in the presence of an adult was seen as subject-object in the child's handling of things.

When research has paid attention to contexts, relations and interplay, findings underline the responsibility of the significant other. The quality of interplay is more foundational for expressivity than are the contextual factors and the disability itself. Further, the quality of interplay is more dependent on the adult's view of the interacting child than the child's acquired communicational skills. Without saying anything about the quality of interaction, Nijs, Vlaskamp, and Maes (2016) showed that child-child interactions increase in frequency when children with severe, multiple disabilities had the opportunity to relate to each other without an adult present in the room. Adapting to the child to promote quantitative as well as qualitative positive interplay is thus an adult responsibility. Acknowledging this responsibility is apparently more important for a holistic view of the child's learning than rehearsing communicative skills.

9 Communication as Causally Linked to Diagnoses When Children Have Severe, Multiple Disabilities

Four studies describe the children's expressions as causal results of their medical diagnoses. Cass et al. (1999) diverge from the others as they place communication at the lowest level in a hierarchical system. The researchers claim that

TABLE 4.3 Communication as causally linked to diagnoses

Papers	Theme
Cass, H., Price, K., Reilly, S, Wisbeach, A. & McConachie, H. (1999)	A hierarchical model for assessing problems
Derby, K., Fisher, W. & Piazza, K. (1996)	Responses enforce self-injurious behaviour
Mount, R. H., Hasting, S., Richard, P., Reilly, S., Cass, H. & Charman, T. (2001)	Behavioural phenotypes in Rett syndrome
Ryan, D., McGregor, F., Akermanis, M., Southwell, K., Ramke, M. & Woodyatt, G. (2004)	The amount of cuing to provide communication with children with Rett syndrome

objective knowledge about diagnostic hallmarks is a foundational premise for teaching the child communicative skills.

These studies approach expressions as causal results connected to the disability itself and include one study of literature, an intervention study, a case study and an observational study. Such causally inspired research literature may shed light on how severe, multiple disabilities can have objective, causal ends. For example, Mount, Hasting, Richard, Reilly, Cass, and Charman (2001) describe how behaviour such as stereotypic, repetitive movements of the hands, sleeping difficulties, teeth grinding and breathing difficulties in girls with Rett syndrome can be understood as genetic phenotypes related to the specific syndrome, or as expressions related to the complex and severe condition of the diagnosis.

Causally inspired research describes communication as objective behaviour closely tied to the child's basic needs, to genetics and to phenotypes. Self-injurious behaviour is not interpreted as expressions of an experienced unease, but as a negative appeal for attention. Cass, Price, and Reilly (1999) describe how weak communicative skills when children have severe, multiple disabilities, are to be placed in a hierarchical order where medical needs such as the function of eyesight, positioning of the body and questions regarding nutrition have to be addressed before communicational skills can be achieved.

Causally inspired research describes important objective features of severe, multiple disabilities, yet, it appears that possibilities for interplay and communication are lost when movements are credited as medical and behavioural cause and effect rather than as subjective, full-worthy expressions. When movements like repetitive hand-movements in girls with Rett syndrome are

described as pure genetic phenotypes, possibilities to include hand-movements into shared interactions are hidden.

10 Ending

Communication and interplay with children with severe, multiple disabilities are subject to investigation within different scientific paradigms, and thus also through different methodological approaches ranging from quantitative surveys to hermeneutic phenomenology. Although research is carried out over a wide spectrum of approaches, it appears that intertwining between interplay and communication is partly accredited, partly wiped out and partly ignored in the research literature. The principal lines in the research literature show how researchers have emphasised communication as skills; intentional, independent and separate from interplay as existential human directedness. There is thus a disproportion that might make the schism between interaction and communication hard to understand to the child embedded in his or her life-world. The same might be said about the child's significant others, which in the words of Merleau-Ponty (2010) have a duty to keep the child safe in the world without encroaching on the child's values. As the encroachment takes place if the adult looks back towards 'past traumas' (Merleau-Ponty, 2010, p. 83), the solution might be paying attention to the child's present situation. If focusing too strongly towards the past or future, the present moment might slip out of the perceptual field of the adult and the possibilities inherent in the life-world of the child.

So, where does the intertwining between interplay and communication lead when children have severe, multiple disabilities? Research is situated in a wide range of paradigms and has provided a wide range of methodological approaches describing interplay and communication. Turning to how interplay and communication are divided for analytical purposes, the lived experiences of interplay and communication are embodied in the relation between the child with severe, multiple disabilities and the sensitive significant other, summing up techniques, contexts, relations and objective medical knowledge.

So, recognising how interplay and communication can be interwoven and given back to the world through movement, we find ourselves in families, circles of friends, at postnatal wards, in kindergartens, in classrooms and in schoolyards, in auxiliary housing, in hospitals, at playgrounds and in swimming pools, together with the child with severe, multiple disabilities. We turn to the research literature and gather important – sometimes vital – knowledge

about well-being and pain, about life and death, about nutrition and medicine, about head switches and about technique, about alternative augmentative communication, about diagnoses, about developmental stages, about perceptual impressions and impressions that create expressions, and about causes and effects. Then, we meet the gaze, the gesture, the mimicry or the movements of the child, a child who is eager, tired, restless, impatient, calm, happy or sad, to, in the blink of an eye, realise that objective knowledge does not contain all that we need to know. How shall we act? From where and from whom shall we seek knowledge to build our decisions upon? The answer to these questions may be placed between objective research and the poetry of everyday life.

The late kindergarten teacher Roger Sivoll (1996) provides a glimpse of an answer in the poem 'Thinking'. 'Thinking' sums up the ambivalent relation between knowing, to know that one does not know, and the relief given by the experience when one discovers that parts of the answer are already given.

So, all of a sudden, one finds oneself sitting, thinking
 if one has to know what one is doing
 to believe in what one is doing,
 or
 at least to believe that one knows what one is doing,
 or if it is enough
 to do what one believes to know
 – and usually, this is where it stops,

but then a kid comes
 fragrant with heavy diapers,
 and then it is obvious

SIVOLL (1996, p. 22, author's translation)

References

- Calculator, R. (2009). Augmentative and Alternative Communication (AAC) and inclusive education for students with the most severe disabilities. *International Journal of Inclusive Education*, 13(1), 93–113.
- Campbell, P. H., Milbourne, S., Dugan, L. M., & Wilcox, M. J. (2006). A review of evidence on practices for teaching young children to use assistive technology devices. *Topics in Early Childhood Special Education*, 26(1), 3–13.

- Cass, H., Price, K., Reilly, S., Wisbeach, A., & McConachie, H. (1999). A model for the assessment and management of children with multiple disabilities. *Child Care, Health and Development*, 25(3), 191–211.
- Derby, K., Fisher, W., & Piazza, K. (1996). The effects of contingent and noncontingent attention on self-injury and self-restraint. *Journal of Applied Behavior Analyses*, 29(1), 107–110.
- Egilson, T., Ytterhus, B., Traustadóttir, R., & Berg, B. (2015). Introduction: Disabled children and youth in the nordic countries. In R. Traustadóttir, B. Ytterhus, S. T. Egilson, & B. Berg (Eds.), *Childhood and disability in the Nordic countries* (pp. 1–11). Palgrave MacMillan.
- Evenesen, K. V. (2018). *Give me a thousand gestures. Embodied meaning and severe, multiple disabilities in segregated special needs education* (Doctoral dissertation). Norwegian School of Sport Sciences.
- Evenesen, K. V., Ytterhus, B., & Standal, Ø. F. (2017). “He is not crying for real”: Severe, multiple disabilities and embodied constraint in two special-needs education units. *Society, Health & Vulnerability*, 8(1), 1387474. doi:10.1080/20021518.2017.1387474
- Fröhlich, A. (1995). *Basal stimulering [Basic stimulation]*. Ad Notam Gyldendal.
- Goffman, E. (2008). *Interaction ritual. Essays in face-to-face behavior*. Aldine Transaction
- Groark, C. J., Muhamedrahimov, R. J., Palmov, O. I., Nikiforova, N. V., & McCall, R. B. (2005). Improvements in early day care in Russian orphanages and their relationship to observed behaviors. *Infant Mental Health Journal*, 26(2), 96–109.
- Hautaniemi, B. (2004). *Känslornas betydelse i funktionshindrade barns livsvärld [The meaning of emotions in the lifeworld of disabled children]* (Doctoral dissertation). Pedagogiska Institutet, Stockholms Universitet.
- Horgen, T. (2006). *Det nære språket. Språkmiljø for mennesker med multifunksjonshemming [The close language. Language environment for humans with severe, multiple disabilities]*. Universitetsforlaget.
- Horn, E., & Kang, J. (2012). Supporting young children with multiple disabilities: What do we know and what do we still need to learn? *Topics in early childhood special education*, 31(4), 241–248.
- Hummels, C., van der Helm, A., Hen-Gevelde, B., Luxen, R., Voort, R., Van Balkom, H., & De Moor, J. (2007). Explorascope: Stimulation of language and communicative skills of multiple handicapped children through an interactive adaptive educational toy. *Digital Creativity*, 18(2), 79–88.
- Karoff, H. S. (2013). Play practices and play moods. *International Journal of Play*, 2(3), 76–86.
- Lancioni, G., O'Reilly, M., Singh, N., Oliva, D., Marziani, M., & Groeneweg J. (2002). A social validation assessment of the use of microswitches with persons with multiple disabilities. *Research in Developmental Disabilities*, 23(5), 309–318.

- Lancioni, G., Singh, N., & O'Reilly, M. (2017). Promoting functional activity engagement in people with multiple disabilities through the use of microswitch-aided programs. *Frontiers in Public Health*, 5(205).
- Lancioni, G., Singh, N., & O'Reilly, M., & Bacani, S. (2006). Teaching 'yes' and 'no' responses to children with multiple disabilities through a program including microswitches linked to a vocal output device. *Perceptual and Motor Skills*, 102(1).
- Lancioni, G., Singh, N., O'Reilly, M., & Oliva, D. (2004). A microswitch program including words and choice opportunities for students with multiple disabilities. *Perceptual and Motor Skills*, 89(1), 214–222.
- Lancioni, G., Singh, N., O'Reilly, M., Oliva, D., Monitroni, G., & Chierchie, S. (2004). Assessing a new response-microswitch combination with a boy with minimal motor behavior. *Perceptual and Motor Skills*, 2004, 98(2), 459–462.
- Lima, M., Silva, K., Amaral, I., Magalhaes, A., & de Sousa, L. (2013). Beyond behavioral observations: A deeper view through the sensory reactions of children with profound intellectual and multiple disabilities. *Child Care, Health and Development*, 39(3), 422–431.
- Lorentzen, P. (2009). *Kommunikasjon med uvanlige barn [Communication with unusual children]*. Universitetsforlaget.
- McFerran, K. S., & Shoemark, H. (2013). How musical engagement promotes well-being in education contexts: The case of a young man with profound and multiple disabilities. *International Journal of Qualitative Studies on Health and Well-Being*, 8(1), 20570.
- Merleau-Ponty, M. (2010). *Child psychology and pedagogy. The Sorbonne Lectures 1949–1952*. Northwestern University Press
- Merleau-Ponty, M. (2014). *Phenomenology of perception*. Routledge.
- Mount, R. H., Hasting, S., Richard, P., Reilly, S., Cass, H., & Charman, T. (2001). Behavioural and emotional features in rett syndrome. *Disability and Rehabilitation*, 23(3–4), 129–138.
- Mumford, L., Lam, R., Wright, V., & Chau, T. (2014). An access technology delivery protocol for children with severe and multiple disabilities: A case demonstration. *Developmental Neurorehabilitation*, 17(4), 232–242.
- Munde, V. S., Vlaskamp, C., Maes, B., & Ruijsenaars, A. J. (2014). Catch the wave! Time-window sequential analyses of alertness stimulation in individuals with profound intellectual and multiple disabilities. *Child Care, Health and Development*, 40(1), 95–105.
- Nijs, S., Vlaskamp, C., & Maes, B. (2016). The nature of peer-directed behaviours in children with profound intellectual and multiple disabilities and its relationship with social scaffolding behaviours of the direct support worker. *Child Care, Health and Development*, 42(1), 98–108.

- Olsson, C. (2006). *The kaleidoscope of communication. Different perspectives on communication involving children with severe multiple disabilities* (Doctoral dissertation). Stockholm Institute of Education.
- Perifano, A., & Scelles, R. (2015). Psychological distress of children with progressive diseases and multiple disabilities: A crossed analyses. *Archives de Pédiatrie*, 22(9), 916–923.
- Pilesjö, M. S., & Norèn, N. (2017). Teaching communication aid use in everyday conversation. *Child Language Teaching and Therapy*, 33(3), 241–253.
- Ryan, D., McGregor, F., Akermanis, M., Southwell, K., Ramke, M., & Woodyatt, G. (2004). Facilitating communication in children with multiple disabilities: Three case studies of girls with rett syndrome. *Disability and Rehabilitation*, 26(21–22), 1268.
- Shull, J., Deitz, J., Billingsley, F., Wendel, S., & Kartin, D. (2004). Assistive technology programming for a young child with profound disabilities: A single-subject study. *Physical & Occupational Therapy in Pediatrics*, 24(4), 47–62.
- Sivoll, R. (1996). *Blant enda flere unger* [Among even more kids]. Pedagogisk forum.
- Skarstad, K. (2018). Ensuring human rights for persons with intellectual disabilities? *The International Journal of Human Rights*, 22(6), 774–800. doi:10.1080/13642987.2018.1454903
- Stasolla, F., Caffo, A. O., & Damiani, R. (2015). Assistive technology-based programs to promote communication and leisure activities by three children emerged from a minimal conscious state. *Cognitive Processing*, 16(1), 69–78.
- Stensæth, K. (2013). “Musical co-creation”? Exploring health-promoting potentials on the use of musical and interactive tangibles for families with children with disabilities. *International Journal of Qualitative Studies on Health and Well-being*, 8. doi:10.3402/qhw.v8i0.20704
- Suhonen, E., Nislin, M., Alijoki, A., & Sajaniemi, N. (2015). Children's play behaviour and social communication in integrated special day-care groups. *European Journal of Special Needs Education*, 30(3), 287–303.
- Toombs, S. K. (2001). Reflections on bodily change: The lived-experience of disability. In S. K. Toombs (Ed.), *Handbook of phenomenology and medicine* (pp. 247–261). Kluwer Academic Publishers.
- Tunson, J., & Chandler, C. (2010). Behavioral states of children with severe disabilities in the multisensory environment. *Physical & Occupational Therapy in Paediatrics*, 30(2), 101.
- United Nations. (1989). *The Convention on the Rights of the Child*. Retrieved February 16, 2018, from <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>
- Wilder, J., & Granlund, M. (2003). Behaviour style and interaction between seven children with multiple disabilities and their caregivers. *Child Care, Health and Development*, 29(6), 559–567.

- Wilder, J., Magnusson, L., & Hanson, E. (2015). Professionals' and parents' shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities. *European Journal of Special Needs Education*, 30(3), 367–383.
- Young, H. (2016). Loss and profound intellectual disabilities: The significance of early separation responses. *Advances in Mental Health and Intellectual Disabilities*, 10(6), 315–323.