Research Paper

Connecting stories: A narrative approach of social inclusion of persons with intellectual disability

Relier des récits : approche narrative de l'inclusion sociale des personnes ayant un handicap mental

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A R T I C L E  I N F O

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A B S T R A C T

Social inclusion is a leading goal of policy and practice in care and support for persons with intellectual disabilities. However, its conceptualization, moral presuppositions and effects are far from clear. In answering the call for reconceptualization, the author refers to cultural-historical, sociological and philosophical analyses on otherness and the other and on their integration in thought, in discourse and in society. An alternative view of inclusion is offered in which the attention is not directed at political, legal, or managerial measures, but at connecting people by opening a dialogue in which life stories are exchanged. In the second part of this contribution, some theoretical foundations of such a narrative approach of social inclusion are developed. Also, preconditions are explored for a space in which a dialogue of life stories may flourish. The role of persons with intellectual disabilities as actors in and authors of life stories is explained. It is concluded that all care paradigms, including the current citizenship paradigm, suffer from a hegemonic dichotomy that frustrates social inclusion. A paradigm of encounter is proposed to underpin policies and practices in which

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RÉSUMÉ

L’inclusion sociale est un des objectifs importants de la gestion et de la pratique de soin et d’accompagnement des personnes ayant un handicap mental. Cependant, l’idée d’inclusion sociale, ses présuppositions et ses effets ne sont pas tout à fait clairs. Guidé par l’exigence de clarté, l’auteur se réfère à des analyses culturelles et historiques, sociologiques et philosophiques de l’altérité et examine à nouveau l’intégration de l’autre dans la pensée, le discours et la société. Une perspective alternative de l’inclusion est offerte, dans laquelle l’attention ne se porte pas sur des mesures d’ordre politique, législatif ou administratif mais davantage sur le dialogue reliant les gens, en ouvrant ce dialogue à l’échange de récits de vie personnelle. Dans la seconde partie de cette contribution sont développés quelques fondements théoriques de cette approche narrative. Sont également explorées les conditions d’un espace dans lequel le dialogue sur les récits de vie peut s’épanouir. Le rôle des personnes ayant un handicap mental, comme acteurs et auteurs de récits de vie est expliqué. Il est souligné dans la conclusion que tous les paradigmes de la prise en charge de personnes ayant un handicap mental, y compris le paradigme de citoyenneté, souffrent d’une dichotomie où s’exerce une hégémonie gênant l’inclusion sociale. Un paradigme de rencontre est alors proposé pour fonder l’idée, et la pratique, selon laquelle prendre soin des liens entre les personnes et leurs récits de vie, et les fortifier, tiennent une place centrale.

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Introduction

The film released in 2005 by the Swedish director Kay Pollack, As It Is in Heaven, includes a scene in which Tore, a young man with intellectual disability, enters a church during a choir rehearsal and announces that he wants to join the choir. The manager of the choir, the boy’s uncle, explains to the choir that his nephew cannot read or write and cannot read music at all, that he is backward, can hardly speak an intelligible word and is a constant burden for others. Moreover, he will bring down the level of the choir, which has just risen somewhat because of the new director. When neither the choir members nor the director see these considerations as sufficient reason to refuse to let Tore join the choir, the uncle loses his temper. He had such great plans for the choir, and that was what he was working for day and night. It would not look good at all to have such a backward boy among them at the yearly choir festival. This choir would never amount to anything.

This scene deviates hardly from what often happens in reality when people with intellectual disability want to participate in communal activities which everyone else takes for granted. The participation of people with intellectual disability not infrequently turns out to be an undermining of existing habits and conventional views and of the social, philosophical and theological ideas that lie at their basis. The breach of ethos is frightening for many people.

Reconsidering social inclusion

For people with intellectual disabilities, the obstinacy of existing concepts of humanity and the accompanying normative views leads to their remaining caught in patterns of care and treatment that...
do not enable them to participate in the ‘family of man’ and to make their own contribution to society. As long as intelligence, grades and level of education are decisive for social success, intellectually disabled people will remain the ‘socially inferior people’ they have been since the nineteenth century. The core problem of social inclusion seems to be the conflict between the lived reality of people with intellectual disability and the normative ethical frameworks that dominate our society. Such frameworks come to practical expression in the roles that are available in society. These roles are predefined through upbringing and education and reflect primarily the views and power relationships of the existing intellectual and material order.

This is even the case in discourses on ‘integration’ or ‘inclusion’. For many years, integration has been the main starting point with respect to policy, management and practice of organized care for people with intellectual disability. But the conceptualization and the moral presuppositions of this policy have not been clear at all (Clegg, Murphy, Almack & Harvey, 2008). With respect to conceptualization, relationships are formed with concepts such as ‘community care’ or ‘community living’. van Gennep (1994) distinguished three dimensions of integration. The first is independent or supported living in an ordinary residential area or neighborhood which he labels as ‘physical’ integration. The use of regular services for education, work, leisure time, and health and welfare care is labeled as ‘functional’ integration. Having available a network of relationships with people other than family members or professionals is called ‘social’ integration. Having available a network of relationships with people other than family members or professionals is called ‘social’ integration. Empirical research suggests that this ultimate goal of social integration has hardly been realized even in situations of full physical integration (Cummins & Lau, 2003). There seems to be a relative independence of spatial location and having social relationships. It probably is the other way around: having social relationships seems to be a more important condition for access to usual community services and facilities – the ‘functional integration’ as it is understood by Van Gennep - than living in an ordinary neighborhood as such. Although the opposite is explicitly what is intended, many practices of ‘community building’ tend towards homogeneity and assimilation (Fendler, 2006, p. 315).

All activities labeled as ‘integration’ or ‘inclusion’ thus occur within a normative framework that is dominated by political, geographical, administrative, organizational and economic factors. In that framework, individual autonomy and freedom of choice predominate. Social and cultural factors are generally underexposed. This one-sided moral frame of reference and the policies based on it do not take into account the concrete interactions between people who are largely strangers to one another. Therefore, it proved able only in a limited way to offer answers to the desire of many people with disability to be counted and to participate in their own living environment, in the social context of their immediate vicinity and in wider society.

This does not mean that integration has failed; it means that both concept and practices need to be seriously reconsidered. Hall also holds that a reconceptualization of social integration is very much needed:

“...social inclusion policy and alternative networks of inclusion both perpetuate exclusion, as the discriminatory contexts are left unchanged and inclusion within people with learning disability networks ignores broader exclusionary processes.” (Hall, 2005, p. 113).

An exploratory analysis

People who are physically, psychologically or cognitively different have always been marginalized throughout history. At the same time, in all periods and all cultures people who are perceived as different have also been presented as symbols of the essence of being human. This paradox constitutes the focus of the analysis that Henri-Jacques Stiker undertook in his book Corps infirmes et sociétés, published for the first time 25 years ago, translated into English ten years ago, but hardly noticed in the Netherlands (Stiker, 1999). Driven by the question why societies attempt to integrate people with a disability, Stiker writes the history of a mindset. What is behind that intention of integration? According to Stiker, integration is a much more important constant in human society than exclusion. It is an arrogant prejudice to presuppose that our time, with its political and managerial striving for the integration of people with disabilities, implies a radical liberation from a preceding period in which people with disabilities were only excluded or eliminated (pp. 15-16). This moralizing ideological position obscures the fact
that exclusion and inclusion can have infinitely different forms and reasons and can sometimes even be two sides of the same coin. For Stiker, the question is what societies say about themselves, if they exclude people in one way or another or if they want to include people in one way or another.

The heart of Stiker's analysis is that in Western thinking the ‘being other’ of people – and every period in the history of Western culture has defined that in its own way – always appears as something that must be assimilated or and thus disappear. A society’s claim to be decent depends on the extent to which physical, psychological and cognitive differences are less visible. This integration can be achieved via various assimilation strategies, but the background of such strategies includes an ideal of a society in which differences between people are erased. Stiker shows that strategies of thinking, speaking and acting can be found in all periods through which it was attempted to have people who deviated physically, psychologically or cognitively adapt to the social norms that obtained for the period in question.

According to Stiker, these strategies of ‘social erasure’ reached their peak in the second half of the twentieth century. The ideal of integration was then based on a principle of rehabilitation that included the notion that all differences can ultimately be erased. That will happen via scientifically developed prosthetics, training and exercise regimes and medical intervention. That will also happen by cultivating the wish of individuals with disability to adapt to current social norms. Our time, according to Stiker, sees the appearance of a culture in which it is attempted to complete the project of identification, of making everyone equal to one another. In his view, this project will result in people with disability being swallowed up into a large and uniform social collective. Physical exclusion would no longer be needed. The technocratically and economically oriented society terms each disability into a ‘support need’ that every citizen may have, therefore something for which no one need be ashamed and which can be provided through administrative, technical and commercial ways. But, Stiker says, behind this smooth social façade the differences, the contradictions and loose ends of existence remain, and people know that all too well (p. 131). The problem in contemporary society does not lie so much in a lack of integration as in forcing an integration through science, technology and politics in which identity in the sense of the convergence of the ‘equal’ and the ‘ordinary’ dominates. The integration that arises via legislation, financing and socialization of care is consequently one of forgetfulness, disappearance, assimilation and conformity. Without saying it in so many words, Stiker sketches a ‘new confinement’ of people with disability: the confinement within the ordinary, the familiar, the socially accepted. According to him, the background of this new confinement includes an ill-considered acceptance of an empirical normality, a logic of the ‘ordinary’ that construes the ‘extraordinary’ or ‘special’ as a threat or a danger, or at least as a necessary evil (p. 143).

Contemporary philosophical and sociological analyses

Stiker’s analysis shows – despite great differences regarding perspective and method – remarkable parallels with Zygmunt Bauman’s sociological analysis of the ‘stranger’ in modern and postmodern culture (Bauman, 1997) and the analysis of philosophical interpretations of alterity by Richard Kearney in his Strangers, Gods and Monsters (2003). Kearney’s main hypothesis is that people project unconscious fears of the strange that they encounter first and foremost in themselves onto others. We do not acknowledge that the human condition consists in being continuously agitated by the confrontation with an alterity, a strangeness that is present in ourselves (Kearney, 2003, p. 5). Instead, we flee by way of various escape strategies, the most important of which is the stigmatization of the other as an outsider, as a stranger who can take on the mythical qualities of a monster or a god. Where Kearney sees a collective cultural unconscious as a basis for the exclusion, Bauman, being a sociologist, is interested primarily in the way in which social and cultural practices make the stranger a counter-image par excellence of modernity: purity, rationality and order. According to sociologists who think along the same lines as Bauman, the ‘postmodern’ idolatry of difference, strangeness and alterity (Kearney, 2003, p. 229) is simply the masking of the domination of new criteria and thus of new thresholds for full inclusion in the culture of modernity. An important criterion behind this so-called ‘postmodern’ thinking consists in the ability and willingness to consume (Bauman, 1997). Other criteria originate from the inclination of our current visual culture for aesthetic normalization and the valuation inherent to that of ideal standards of beauty, health, youthfulness and genetic perfection (Hughes, 2000;
Hughes, 2002). Such criteria often prove to be fatal for the way in which people with disability are seen.

Returning to Stiker from this small detour via Bauman and Kearney, we notice the following. What we would consider processes of exclusion in social reality, he defines as integration strategies on the level of thought. Our culture understands strangeness and difference only by normalizing them, obscuring or eliminating them, by underestimating or overestimating them (Stiker, 1999, p. 183). And conversely: much of what is presented in politics and care policy as integration strategy is nothing else than a cosmetic artifact that is to mask the stubborn reality of exclusion from the prevailing conceptions of the world and humanity. Joel Kahn (2001) points to the paradox that, because of its embeddedness in concrete and historical circumstances, the modern idea of a universal humanity encompassing all diversity, as expressed in rationality and autonomy, always has its ‘others’ and thus brings with it processes of social exclusion. “In this sense, universalism is a culture like any other, differing only in that it always fails to recognize itself as such” (Kahn, 2001, p. 23). As this recognition fails, those who are excluded must be brought back from the periphery to the homogenized and idealized centre of society. Stiker speaks in this context of a ‘technocracy of absorption’ (Stiker, 1999, pp. 132, 164, 192). There seems to be hardly any awareness of the exclusion mechanisms implied in this technocratic strategy.

A provisional definition of social integration

It is remarkable that analyses, such as those by Stiker, Bauman and Kearney are almost entirely lacking in political, scientific and policy discussions concerning the integration of people with intellectual disability. There are, however, important reasons for breaking this silence. Such analyses challenge us to define more sharply what we are talking about when we talk about social integration or inclusion. They can open our eyes to the pitfalls of an integration philosophy that is not very conscious of its disciplining, assimilating and normalizing meanings and functions and of its one-sided concentration on the physical/spatial dimension of integration. These analyses have a practical meaning because they can serve as a critical mirror for current political and organizational practices. They thus point out a way to practices in which people with disabilities cannot simply be made invisible or even eliminated but in which the dialogue is opened with the unusual or the unnamable, with that which evokes resistance.

Thus these analyses contribute to a new view of social integration in which the attention is not directed primarily at setting up the government apparatus, the infrastructure of care economics or the organization of care but at connecting people. Traces of such a view of the discourse on social inclusion/exclusion can already be found in reflections of a number of social scientists and philosophers on racial or ethnic diversity. I will describe this view in terms of the following provisional definition. Social integration is not a characteristic of a situation or of people in a situation. Rather, social integration is an interpersonal process that helps to acknowledge and value people who feel themselves strangers or are seen by others as strangers in their uniqueness, thus not in spite of but with the characteristics (limitations and differences) that are perceived as strange.

This definition implies a breaking up of each suggestion of a conditional or causal connection between the so-called ‘physical’ and ‘functional’ integration on the one hand and social integration on the other. It offers space to assess activities that concern ‘physical’ and ‘functional’ integration in the light of their actual contribution to social integration. Conversely, it offers insight into the processes of social integration as the condition of possibility for functional and physical integration. At least as important is the fact that such a definition removes the appearance that people who live or stay in a protected environment – and that is often people with serious intellectual or multiple disabilities – are not or should not be involved in processes of social integration. A perspective of social integration as an interpersonal process is that people who live with disability will participate in a community that provides a positive contribution to their search for a meaningful existence and that they are accepted and recognized in their contribution to that community.

In this view of social integration, all emphasis is placed on interpersonal processes and the social and cultural aspects they entail. For future practices of contact with people with disability (Stiker, 1999, p. 195f) recommends to bring into motion processes and initiatives that help the social fabric
around people with disability to accept differences. I will argue that life stories can play an important role in these processes and initiatives. They have the potential to open the dialogue with the unusual and thus to create connections between people. As Pols, Miedema and Levering state: "Stories can show how the ordinary and the exceptional can exist beside each other. Stories always concern the special integration of the normal and the deviating. The crazy and the bad, the boring and exciting, the morbid and the terrifying can be discussed in the story. The story is able to show the ordinary and the exceptional. The story can take the exceptional from its situation of rejection in which it has been pushed by the scientific report or by general opinion. But the story is also able to show what is exceptional about the ordinary." (Pols, Miedema, & Levering, 1995, p. 15).

Connecting stories

Social integration as an interpersonal process, as I have described it, arises and flourishes where stories about people are told and heard. In this context the term ‘stories’ refers primarily to people's life stories. By linking social integration with life stories, I am joining a broad tradition of narrative approaches in theology, philosophy, literary studies, social sciences and, in particular, ethics. In that tradition stories are seen as constitutive for the identity of persons and groups (Kearney, 2002; Meininger, 2006; Polkinghorne, 1988; Ricoeur, 1986; Ricoeur, 1988; Ricoeur, 1990). In the practices of storytelling I discuss here, it is primarily this identity constituting and socially connecting function of storytelling that is at issue. This is, of course, not separate from the function of representation but it does not merge with it entirely (Kearney, 2002, p. 153). The question I want to answer is: what, in stories, is connected with what, who with whom and also who is connected with what?

Stories connect the storyteller with his/her own life

Telling the story of a life is, in the first place, connecting disparate events in time and space so that they form a coherence that can be described by concepts like 'plot' or 'story line'. It is an attempt to experience the coherence of life in a narrative way (Kearney, 2002, pp. 129–131). In that sense, telling a story is the same as connecting: a synthesis is sought in the plurality of events, actions, encounters, plans, successes, failures, unintended consequences and interactions. When telling a story, I connect myself with what is strange in myself as well, the other that disquietingly determines me, that is present and evades my grasp. Here fragmentation, discontinuity or breaks cannot be ignored: it is not a matter of constructing a unity but rather one of seeking connections. This quest consists in experiments of selection and reorganization in which one attempts to transcend the pure succession of events, the unconnectedness of ups and downs and the present experience of them in an imaginative way. Telling a story makes the real world a world of meanings and of possibilities. This is the 'mimetic' or re-creative function of the story (Kearney, 2002, pp. 131–135). In telling a story, one spans an arch between memory and expectation, between coming to grips with the past and looking into an unknown future. Second, in telling stories, a connection occurs between the storyteller and the configuration that occurs in the story. The storyteller does not represent himself but yields himself physically as the narrator; he makes himself present as the author of the story: this is my life, this is who I am, this is my doubt, my hope, my struggle. In this unique way, I am connected with myself and at the same time a stranger to myself. Stories thus connect the events in a significant way and stories connect the storyteller to the narrated configuration of the events that the narrator is.

Stories connect storyteller and listener

A plurality of connections with other people and other worlds is embedded in the connections cited above. Stories connect because they are always addressed and situated: they are always told to someone and they are told in certain contexts. The meanings ascribed by the storyteller are addressed meanings, i.e. meanings that are intended to be shared and responded to. This has consequences, of course, for what is told and how it is told: in the narrative situation the conventional roles and distinctions, such as the distinction between ‘care provider’ and ‘client’ can be temporarily breached. Stories make the storyteller and the listener into someone else by, among other things, offering them
the opportunity to walk in someone else’s shoes and to experience the lot of the other in concern and distance, as if we are the strange other. Kearney calls this the catharsis function of the story (2002, pp. 137–142). He holds that this ability of stories to move us to empathy with the strange other – the stranger, the better, he says literally – not only implies an appeal to our imagination but also to our moral sensitivity (Kearney, 2002, p. 139; Ricoeur, 1990, pp. 193–198). Storyteller and listener are both addressed with respect to their understanding of the other and also their self-understanding. In the strange other, they encounter at the same time the strangeness in and alienation from themselves (Ntourou, 2007, p. 233).

Stories connect storyteller and listener to others

Stories also connect the storyteller and listener to others, because the events that are being narrated consist primarily in encounters with other people and other worlds. Telling stories always proceeds via the other. Someone tells who he is by telling others about his relationship to other people and other things and circumstances. He is not an isolated individual; he is a son, brother, husband, father, friend, student, colleague, spectator, fellow-sufferer. The way to myself is a way that runs inevitably via the other. And the other is always someone who, just like me, tells who he is through his story about his relationship to me and to others. People do not only participate in one another’s stories; the story of the one constitutes the story of the other. People thus receive their existence from one another. Remembering, narrative remembering, is a social practice par excellence (Middleton & Hewitt, 1999).

In telling stories, therefore, both the identity of the storyteller as well as that of the listener comes into play, as well as those of others who play a role in their stories.

Stories connect storyteller and listener to judgments about the ‘Good Life’

Stories connect because in addition to being a social practice, storytelling is also a moral practice (Kearney, 1999). Stories imply claims to a morally meaningful social existence and not infrequently include explicit moral commentary. Because the story is addressed, storytelling is implicitly also always a persuasion: the view of the world that the storyteller presents to the listener or hearer is never ethically neutral. It invites the reader or listener to a renewed evaluation of the other, himself and the world. It attempts to move the reader or listener to a certain moral judgment of the characters and their actions. Stories thus always contain claims with respect to the good life in an ethical sense – claims that are grounded in the personal engagement of the storyteller. At the same time, it calls the listener or reader to relate to the different proposals for the good life with and for others in just institutions that come to expression in stories (Ricoeur, 1988, p. 249). Such claims can sometimes bring moral differences to light that lead to a break between people. They can also lead to redemption, reconciliation and restoration. In any case, the event of telling and retelling stories has consequences for social relationships.

Stories connect storyteller and listener to suprapersonal stories

The nature and possibilities that stories have to connect different times, places and people with one another are also determined by the web of metanarratives of which all our stories are part and with which they are connected through visible and invisible threads (Baldwin, 2005). By metanarratives I mean suprapersonal stories that people understand by means of a more or less fixed concept of humanity, disease or theory. A culture has ‘pre-scribed’ stories about what is ‘normal’, ‘adjusted’, ‘healthy’, or simply ‘sick’, ‘insane’ or ‘monstrous’. People are not only a source of stories; they are also the subject of political, scientific and cultural stories. Such stories derive their content from countless private stories. They also influence the stories and thus the personal identity of individuals and the collective identity of groups in society. The connection can be so formulated that the metanarratives ‘prefigure’ the narrative aspect of individual life. Ricoeur views this prefiguration as a first step in the threefold ‘mimesis’ of prefiguration as the ‘pre-imaging’ of the story, configuration as the telling of the story, in which someone becomes partly detached from the prefiguration and refiguration as the renewed creative turn to the reality of one’s own existence (Kearney, 2002, p. 133). Thus, personal
identity is an important factor in politics and, conversely, politics is always closely connected with personal life stories. We cannot understand an individual life if we do not also consider it as part of a social and public sphere. Moreover, people are subjects of scientific stories in which being human and life in this world are often portrayed as a system of objectifiable structures and functions that can be identified and compared. There, all attention is directed to those aspects in which people are the same and to that which connects them to nature. These scientific stories contain series of assertions about the ‘what’ of the human being and thus also about the ‘what’ of individual variations, the ‘what’ of deviations, disturbances, diseases or defects.

Stories connect storyteller and listener to religious stories

In life stories, storytellers often connect themselves explicitly or implicitly with stories that are even more encompassing than the above-mentioned suprapersonal metanarratives. I am referring here to religious narratives, which are also called ‘master narratives’. By this term, Kearney (2003) refers to the great mythical and religious narrative traditions that are the formative forces of cultures and portray people in relationship to the cosmic or the transcendent. Aside from the fact that they are suprapersonal, they also testify to an involvement with a reality that is experienced transcendentally and can be expressed in various forms of religious life. In religious stories of different traditions, God is present as a transcendent reality that is related to our reality and to all interpretations of it. This involvement with transcendence makes it possible to see and experience in new ways the ‘ordinary’ reality that arises in one’s own life story but also in all the metanarratives with which it is interwoven. Life stories also manifest their profound relational character where they touch or are connected with religious stories or aspects of them. The relationship with God or the divine in the story is experienced as a relationship that radically affects one’s self-image and all relationships with others and with reality.

Metanarratives and master narratives in relation to people with intellectual disability

The lives and life stories of people with intellectual disability are – just like those of all of us – closely connected with metanarratives of various kinds. They are, for example, interwoven with the political metanarrative that characterizes them as vital and mature citizens in a modern democracy; but they are also interwoven with the economic metanarrative that portrays them as consumers in a care market that reacts flexibly to their preferences. They are intertwined with the biomedical metanarrative that describes them as impaired or disturbed, deviant or dysfunctional. They are intertwined with the social metanarrative that portrays them as unadjusted, as dropouts, as a collective burden or as socially superfluous, but also sometimes as heroes who overcome their limitations and achieve their dreams. They are interwoven with the metanarratives of the ideology of care that view them as fellow human beings who are to be cared for, developed, emancipated, empowered or supported. Stories of people with disability are, finally, interwoven with religious master narratives and their culture- and time-bound interpretations. These can be stories in which disease and disability are viewed as punishment for sin, as purifying trials, as the work of the devil, or even as a gift that entails a task.

Without connections to such metanarratives, people cannot become the source of narratives that they as people are, regardless of whether they have intellectual disabilities or not. Nevertheless, it appears from this consideration that such metanarratives can also be serious hindrances. That happens in particular if such a metanarrative has hardened into a cliché or if it is viewed as a stereotype in which all personal narratives are to fit or should fit. In such a context, it is adequate to speak of narrative denial or expropriation, and institutionalized narrativity. It is a form of narrativity from which all doubt, relativization, nuancing, ambiguity and contradiction have been filtered away. Thus, the life stories interwoven with that form of narrativity can become constricted in the straightjacket of simplicity. Connecting is then perverted into annexation and assimilation. Metanarratives then no longer invite one to dialogue, imagination and reinterpretation but drive one into subjection, adjustment and imitation.

Thus, metanarratives sometimes constrain and subjugate people and sometimes they liberate and emancipate. And it is of great importance to know what the difference between the two is (Kearney, 2003, p. 179). The search for that difference requires a hermeneutics, a continuing process of explaining, a practice of moral reflection and moral imagination. The ‘better story’ always needs to be
found via reinterpretation and retelling. It is better in the sense that it connects more adequately than a previous story to the perspective of a meaningful existence. Not only are the storyteller, the listener and their life stories involved in that hermeneutic. The reality mediated by the story is also involved, as well as the individuals and their relationships involved in that reality. Thus, metanarratives and master narratives are subject to a continuous reinterpretation. Narrative ethics then is not primarily an ethical theory but a hermeneutical practice that searches for the proper relationship, in the proper context, at the right moment, with taking proper proximity in the distance from, and proper distance in the proximity to the other and to the metanarratives and master narratives that are interwoven with the story of the other and of oneself as listener (Meininger, 2005, pp. 109–112).

In summary: stories connect people in several ways with themselves, with one another and with human life and society in culture and society. In this connecting telling of stories, the strange is not denied or shoved aside but met in the conversation of people with themselves and with others. That does not mean that every connection that is made is also humane, beneficial and promotes processes of social integration. It does mean that no process of social integration is conceivable without having its starting point in a careful hermeneutics of the voice that is heard in the life story, the life world that is unlocked by the story and the connections that the story implies or to which it invites the listener. The ignoring or underestimating of stories of people with intellectual disability as well as the powerlessness or even unwillingness to listen to those stories is a serious hindrance to each prospect of renewal of engrained conventions and ideas.

**Connecting stories: an event within practices**

I have defined social integration as an interpersonal process in which the conversation with the stranger is opened. Now I discuss the question of where this narrative event is localized and what this means in social integration processes of people with intellectual disability.

The conversation with the stranger constantly arises within different social and societal life areas and the practices cohering with them. It can concern practices within the family or wider family, school, professional training or hobby courses, work, friends, the church, the mosque, the sports club or supporters' club. Sometimes, such practices are set up specifically for people with intellectual disability with this goal in mind. That can be of shorter or longer duration and organized or not by or with the help of professional care givers: friends, buddy projects, coffee groups, ‘multilogue’ meetings (Kal, 2001), open houses, social network projects and various initiatives in the sphere of education, work, leisure time activities and faith communities as well as within existing forms of care provision and social services. Assuming we know that the pure existence of these ‘inclusive’ practices does not in itself guarantee that they are actually a space for connecting stories, the question is now: under what conditions do these practices actually invite people to tell their stories, to listen to them, to exchange and to connect and what role can people with intellectual disability play as actors?

**Space between the logics**

People's stories can be connected with one another if there is room to allow the stories to be told and even to listen to them. ‘Space’ is needed. That space must be created within all the cited practices. But what kind of space is that and where is it situated? As far as situating is concerned, we can state that in any case it concerns a social space, (which of course presupposes the presence of physical and temporal space). Both Kearney and Stiker state that acceptance of and respect for differences cannot be expected of collective social structures. They are skeptical regarding the political and administrative organization of integration because it ignores the social exclusion that is part and parcel of our culture. Edward Hall has pointed to this by stating: “While social inclusion policy is concerned with providing access to the (economic) spaces of the majority, it pays little attention to the structures and attitudes that dominate in such spaces, the transformation of which people with learning disabilities arguably desire.” (Hall, 2005, p. 113).

Only in a direct social environment in which people are not anonymous to one another can people separate themselves from the disciplining, assimilating and annexing forces that dominate in a society. Stiker (1999, p. 199) speaks of ‘black markets’, of a ‘shadow economy’ of social relationships, a social
space that consists in an ‘underground network’ of small-scale local initiatives that runs through all state institutions, the market, the public sphere, ‘civil society’ and the private domain and that is not concerned with the dividing lines that are drawn in theory and practice between these areas. The space at issue here can be described best as a space in between, a niche or sanctuary that would indeed be helped by a material embedding (in services, social institutions and buildings) but does not derive its existence and nourishing sources from that material embedding. For this kind of space, Michel Foucault has used the term ‘heterotopia’ (Foucault, 1986). The German special educationalist Dreher speaks in this connection of an ‘A-topia’, the space between a starting point that represents the ordinary and familiar and an uncertain final destination in which the transformation into inclusive thinking and acting will be completed (Ntourou, 2007, p. 255).

The special educationalist van Weelden already saw that more than 20 years ago, arguing for what he called a ‘space for intimacy’ (van Weelden, 1986, p. 45). That refers to a space where people with disability can meet others in such a way that the prejudice and resistance invoked by the mutual strangeness can be faced up to. In such a space, an interaction can occur in which the uniqueness and strangeness of the partners is recognized and not subjugated to the yoke of general ideas of ‘ordinary everyday life’, ‘normal existence’ or ‘integrated living’. Such a ‘space for intimacy’ is, according to van Weelden, formed primarily by people who are in a personal relationship with the person with disability: parents, family members, friends, as well as teachers, supervisors, caregivers and others. It is the space where stories are told, can be connected with one another, and thereby can create new moral space. As a consequence, a transformation in thinking, speaking and acting can occur that invokes new meanings and a new way of acting in life and society by all those involved. Uniqueness, strangeness and communality can then develop into a configuration in which the one dimension does not overshadow or suppress the other (Ntourou, 2007, p. 257).

Countering processes of marginalization and exclusion, such a space, niche or sanctuary has the potential to make and nourish connections between people in which difference and strangeness are allowed to remain. Some characteristics of such a space are the following (Kal, 2001, pp. 52–75):

- the person with intellectual disability knows that he or she is welcome, even if he or she is not able to express joy, suffering, lack and desire in line with the prevailing codes and in recognized vocabulary. That which remains without speech and vague is not denied by actively shouting it down. Others will expose themselves to it and come through it with perseverance. Accommodation is offered to people who cannot be ‘accommodated’;
- the space is characterized by hospitality. People have time; there is room to offer emotional support and communal activities are sought that can be experienced as meaningful. People are enabled to experience themselves as acting subjects and thus to develop self-esteem;
- the space is characterized by a suspension of the goal-means rationality that is determinative for organized care and support. It does not concern producing ‘evidence-based’ effects of care and support methodologies, ‘making something’ or ‘producing something’, but being present and together experiencing that which is considered to be of value. In such a sanctuary, the ideology of normality is suspended. The ‘Stachel des Fremden’ remains a thorn in the flesh of the culture of self-sufficiency and emancipation, independence and rationality (Waldenfels, 1998). It remains a continuing appeal for a response that cannot find purchase in what is known and familiar;
- in all of this, this space is a space for dia-logue, literally, a ‘speaking among’, that moves among or between different logics. The dialogue derives its transforming effect not from the arrangement of a certain discourse but from its disturbing and offensive but sometimes also liberating ability to put all logics in the shade (Ntourou, 2007, pp. 253-254). That is the transforming experience that parents witness when they relate that life with their disabled child has taught them to look at the world and themselves in an entirely different way. And fortunately, that experience is not only reserved for them.

In such a space, the connecting power of stories can blossom in a beneficial way. Everything that is done in society under the adage of social integration deserves the name only if it has the characteristics of this space. It can be created in families, schools, church choirs, faith communities, neighborhoods and societies, as well as in traditional protected forms of living and care. It can be organized as a
fordable place in the great stream of dominant conventions and views. Then, all the practices cited can become places of and for all those concerned, places where loneliness and social superfluity can be actively combated. These ‘other spaces’ function as a mirror for all those spaces that are considered ‘real’ or ‘normal’ (Foucault, 1986, p. 24). Such a space consists primarily of people who have gradually discovered or want to discover that the disruption by the strange, the unsuitable and what cannot be accommodated brings its own order. These are people who want to be reminded of the fact that they themselves are strangers (Meininger, 2008). Concrete examples of this kind of spaces can be found in all those encounters, places and events where ‘being with’ persons with intellectual disabilities is emphasized instead of ‘doing something for’ them. These spaces can be found where intrinsically motivated people choose to share (part of) their life with people with intellectual disabilities as for instance in the communities of l’Arche (Reinders, 2008), or in buddy programs or friendship circles (Novak Amado, 1993; Perske, 1988). But even within a professional care setting sometimes niches, moments and personal encounters can be found that disclose a space for storied dialogue.

**Actors: people with intellectual disability**

The contextual diversity of this space ensures that all kinds of actors can play a role in it. Each of the actors merits attention, but I want to take a closer look at the most important actors: people with intellectual disability. Although stories have intrinsic connecting powers, it is precisely the stories of such people that seem to be particularly vulnerable in practice. They are scarcely heard, because they seldom or never meet the norms of articulative ability, rationality and coherence that prevail in usual social discourse. That vulnerability is stronger for those whose very ability to be the authors of their own life stories is doubted.

I will point to only a few aspects.

First, the hindered ability for narrative expression and communication plays a role. Baldwin (2005, p. 1026) points out that this is true only if narrativity is viewed one-sidedly as verbal action. It would be a misconception to think that the connecting power of stories applies only to those who are able to tell a reasonably coherent story through using words and not, for example, to people with profound multiple disabilities. If verbal communication is hindered, there are many non-verbal interaction methods available that can help someone tell his or her own story. It is important here that we do not set a standard beforehand for what can be called a ‘story’ but pay attention to the ‘little stories’ that are concealed in the everyday. People who do not speak often possess a range of non-verbal, physical and symbolic forms of expression that admit a narrative explanation. Non-verbal behavioral expressions, however, are seldom seen as a story because of, for example, the strange codification which can be extremely uncontrolled in one person and extremely inhibited in another. In such cases expressions are not heard or read in a narrative way, i.e. with a view to the internal and external connections that are contained in stories. It requires the conversation partner to ‘listen to whispering’, which presupposes a subtle feel for messages in tiny or on the contrary in grotesque signs, a listening that helps in configuring the life story.

A second aspect concerns the doubt of such people being able to be the authors of their life stories at all. We saw above that ‘text’ can refer to expressions in narrative practice that are entirely different from the spoken or written word that, for that matter, in itself already refers to physical processes in which a person opens himself up for another. Moreover, if we realize that a text comes to completion only in the embodied appropriation by the reader or listener, then there is no reason to deny people with intellectual disability, even if they have profound multiple disabilities, authorship over their life stories. Of course, the access to authorship, the ‘who’ of the person with disability, makes unusual detours necessary. But more fundamental is that each person – already only because he or she is a child of parents – is in any case the co-author of the life stories of those who live with him or her. Conversely, each person consists to an important extent of the stories that others tell about him or her and the others are, in turn, co-authors of his or her story. The questions that intellectual disability entails with respect to the telling and connecting of stories thus do not have to be denied or trivialized. It is important to view them from the perspective of the interwovenness of all our life stories.

A third aspect concerns the dialogical and mutual character of the connecting of stories. Dialogue should not be burdened either with normative ideas about mutuality as a deliberative relationship of
exchange in which giving and taking are balanced. Such criteria do exclude in advance many people with intellectual disability from all dialogue. True dialogue cannot be connected with criteria as a shared starting point or a common aim; it requires radical openness. Dialogue with people with intellectual disability – and by the way also dialogue with all others – is not concerned with a relationship of exchange but with a relationship of response. It is precisely the difference, the strangeness, the lack of equality, the asymmetry in experience, social position and language, the feared breach of the ethos, the always incomplete response to the appeal of the other, the hope for and the amazement about a possibly new perspective that are driving forces behind dialogue. Wherever dialogue is carried out in this way people with intellectual disability are full partners. The partners with disability pose the question to others as to how responsive they actually are if they make their views and conventions with respect to education, work, care, being church, as well as those with respect to participation in sports, doing science or making love the norm for everyone.

People with intellectual disability are actors in the processes of social integration. But processes of social integration can come into existence and blossom only in interaction with all other actors. The burdens of this process must not be shifted one-sidedly to people with intellectual disability. The learning process to be undergone is also a learning process for all those others in society who do not bear the label 'intellectual disability'.

A paradigm of encounter

Current professional care is only able to give form to the space of dialogue if existing care paradigms are transcended, including the technically and methodologically oriented forms of implementation and the strongly managerial and functionally fragmented forms of organization they have produced. At the background of the medically-oriented defective paradigm, the behavioral science-oriented development paradigm and the politically-oriented support paradigm there is a persistent basic assumption of hierarchy and hegemony. This basic assumption is that people without disability, whether they be doctors, educationalists or support workers, have something that people with disability do not have and that the opposite is not the case. This basic assumption lives from binary distinctions between autonomy and dependence, normal and abnormal, self and other as separate individuals. It overlooks how relationships that people without disability would judge as dependence relationships in a negative sense can, from the perspective of people with disability, entail connections that in fact strengthen their subject status. These dichotomies cohere closely with a subject-object schema that can be found in the rehabilitation idea that, according to Stiker's analysis, determines the image of care and support in our time. This schema is encountered no less in the care paradigms that have been distinguished in recent decades, including the current citizenship paradigm. In contemporary thought, the hierarchy and hegemony seem to be opposed by the view of persons with disability as clients in a market, as full fellow citizens, as mature consumers who purchase care like a commodity. This metanarrative, however, is many cases nothing more than a concealment of differences between people that should be relevant – politically as well. It runs the risk of deteriorating into a rhetoric that obscures the development of new forms of dependence. We see these new forms of dependence arise where people with intellectual disability come up against the limits of the struggle to be 'just like everyone else', the limits of the idea that they can have unlimited freedom of choice and complete control over their lives. We see the new dependence arise in the loneliness, poverty and social superfluity from which many people with intellectual disability suffer and in the abuse that is made of them in various forms, regardless of the place where or the setting in which they live or stay.

To the extent that professional care reflects such a hierarchical division – and this is often the case – it is not able to set up, nourish and look after spaces for intimacy. But it is not by definition the case that professional care is not able to do so. Professional care can be dignified and dignifying. Care providers can become attentive listeners to the stories of their clients. They can, together with their clients, search for beneficial interpretations of that story by connecting it with the stories of others and with their own stories. But if professional care is going to be able to do that, then it needs to say farewell to the categorical subject-object schema that lies within each of the cited paradigms. To a considerable extent, it has to leave the professional goal–means rationality that reproduces this schema. It means that in the content and the organization of its medical, educational and supporting
care professional care needs to seek its starting point in a ‘paradigm of encounter’ or better yet, in ‘encounter’ as such, for each paradigm runs the risk of hardening into a doctrine. Care paradigms that remain fixated on activities that normal, healthy, integrated people should undertake for deviant, sick or excluded people, stand in the way of truly meeting one another and living together. Encounter as the supporting foundation opens up professional care and its organization for contributions to social inclusion. Then professional care can apply itself to what it still does not see enough as its core task: taking care of and nourishing beneficial connections between people and their stories.

References


