

A Normative Account of Inclusion
About the Inclusion of People with Disabilities in Society

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1. Introduction

From the second half of the past century the position of people with disabilities in society has been of concern to disability rights activists and scholars. This thesis contributes to this debate by developing an account of inclusion. Exclusion has been identified as a problem for people with disabilities by many different authors.¹ But not much has been written about inclusion as something that encompasses what is required to improve the position of people with disabilities in society.² Therefore I research whether it is possible to develop an account of inclusion that gives substance to what it is disability rights activists strive for.

In contemporary western societies people with disabilities have a lot more opportunities in life than has been the case in the past. Still, people with disabilities are confronted with situations that testify of society being insufficiently responsive to differences between people. How can one not feel subordinated or an outcast when one is not provided access to a building, to which the majority of people does have access? Or when others are surprised about one participating in a practice considered to be normal for other people?

People with disabilities are part of society. But what does it mean to say that they belong? When can you say that people with disabilities are included in society? In this thesis an answer will be provided to the question: *what does inclusion of people with disabilities in society mean?* The aim of this thesis is to answer this question by developing an account of inclusion. In order to develop such an account a justificatory basis for the normative content of the account should be provided. Subsequently, a

¹ See Elisabeth S. Anderson, "What Is the Point of Equality?" *Ethics* 109 (1999), 287–337. Mike Clear, *Promises Promises: Disability and Terms of Inclusion* (Sydney: The Federation Press, 2000). Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability: Inclusion, Access, Diversity, and Civil Rights* (Westport: Praeger Publishers, 2005). Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency*. (New York: Routledge 1999). Deborah Marks, "Disability and Cultural Citizenship: Exclusion, 'Integregation' and Resistance," in *Culture and Citizenship* ed. Nick Stevenson 167 - 179 (London: SAGE publications Ltd., 2001). Anita, Silvers, David Wasserman and Mary B. Hahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (Lanham/Oxford: Rowman & Littlefield Publishers, 1998).

² Arie Rimmerman, *Social Inclusion of People with Disabilities: National and International Perspectives*. (New York: Cambridge University Press, 2013), 35.

clear definition of inclusion has to be presented. Furthermore, it should be explained how the developed account of inclusion can be used to evaluate the position of people with disabilities in society. Finally, it has to be made clear what realizing the inclusion of people with disabilities in society requires.

My starting point consists of three conceptions of equality developed by Anita Silvers,³ Elizabeth Anderson⁴ and Eva Feder Kittay⁵ that provide the justificatory basis for the normative content of my account of inclusion. Each of these authors points at a different way in which people with disabilities are unjustly excluded from society. By exploring the instances of unjust exclusion one gets an idea of what inclusion consists of. From each of these three theories a different principle of inclusion is abstracted. The three principles of inclusion are brought together into one notion of inclusion, that is able to address all the issues covered by the three theories of equality separately. The thus obtained notion of inclusion provides a more encompassing basis than the three theories of equality separately for diagnosing unjust practices of exclusion, because these three theories were not able to address the problems the other theories did address. Moreover, this notion of inclusion prescribes how people can relate to each other in accordance with everyone's equal moral worth. Everyone is of equal moral worth, therefore everyone should be included in society.

In chapter 2 it is argued that inclusion consists of three principles – the *recognition of equality principle*, the *participation principle* and the *needs principle* – which are found in Anita Silvers' theory of formal equality,⁶ Elizabeth Anderson's theory of democratic equality⁷ and Eva Feder Kittay's theory of connection-based equality⁸ respectively. These authors provide a firm justificatory basis for the principles that together form the requirements of inclusion.

In chapter 3 it is claimed that one is included if: one is recognized as an equal (*recognition of equality principle*); one is not excluded from participating as a peer (*participation principle*); and the needs one has are taken into account (*needs principle*).

³ Anita Silvers, "Formal Justice," in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* 13 – 145 (Oxford: Rowman & Littlefield Publishers, 1998).

⁴ Elisabeth S. Anderson, "What Is the Point of Equality?" *Ethics* 109 (1999), 287–337.

⁵ Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency*. (New York: Routledge 1999).

⁶ Anita Silvers, "Formal Justice."

⁷ Elisabeth S. Anderson, "What Is the Point of Equality?"

⁸ Eva Feder Kittay, *Love's Labor*.

With these three principles at hand, in chapter 4, it is attested that establishing the inclusion of people with disabilities in society consists of fulfilling the requirements of inclusion at three different levels. Social, physical and political inclusion have to be established.

In chapter 5 it is argued that the inclusion of people with disabilities in society does not take away all difficulties associated with disability. Still, the three requirements of inclusion can function as guidelines in dealing with disability related issues that do exist in an inclusive society. How this can take shape in the organization of long term care is discussed in chapter 6 with a case study of the personal assistance model based on direct payment.

I consider it to be important to approach the position of people with disabilities in society from the perspective of inclusion. Because inclusion is something positive, it embodies an ideal waiting to be realized. And there are positive developments with regard to the position of people with disabilities in society, such as the adoption of the UN Convention on the Rights for People with Disabilities.⁹ I think it is time to consider what the final goal, disability rights activists strive for, can be. I think inclusion embodies this final goal. Equality cannot encompass such a goal because either it cannot be realized for everyone or it does not entail equal treatment and equality in participation which are both very important for improving the position of people with disabilities in society.

⁹ Convention on the Rights of People with Disabilities (adopted 13 December 2006, viewed at <http://www.un.org/disabilities/convention/conventionfull.shtml> in June 2014).

2. Equality and Inclusion

By making claims for justice based on equality, Anita Silvers¹⁰, Elizabeth Anderson¹¹ and Eva Feder Kittay¹² show us how certain groups in society are marginalized. Their analysis of the injustice of exclusion in terms of equality is discussed in this chapter, in order to get a better understanding of what a notion of inclusion consists of. By analysing these different conceptions of equality, it becomes clear how all of them emphasise a different aspect of inclusion.

First, Anita Silvers' conception of formal equality is explained. By claiming equality for people with disabilities, Silvers wants to eliminate exclusion that resulted from an unequal treatment of people who differ from the majority. According to her, people with disabilities have not been recognized as equal citizens with the same rights as able-bodied citizens. What stands out is that her notion of equality does not take able-bodied people as a reference group setting the standard for the organization of society. According to her, equality requires that society should be organized in such a way that no one faces any difficulties that result from being different from the norm. From Silvers' account of formal equality it becomes clear that inclusion means that one is *recognized* as an equal member of society. This is called the *recognition of equality principle*.

Second, Elizabeth Anderson's conception of democratic equality is considered. She proposes a relational account of equality in which being equal means standing in relationships of equality with others. Such a relationship requires certain capabilities to be present in order to be able to participate as an equal citizen. For some people with disabilities, having these capabilities can only be realized with the help of certain aids or support. The problems Anderson addresses with regard to people with disabilities are injustices resulting from the absence of certain capabilities that results in marginalization of people with disabilities. From Anderson's account of democratic equality follows that inclusion is strongly connected with being able to *participate* as an equal member in society. This is called the *participation principle*.

¹⁰ Anita Silvers, "Formal Justice."

¹¹ Elisabeth S. Anderson, "What Is the Point of Equality?"

¹² Eva Feder Kittay, *Love's Labor*.

Finally, Eva Feder Kittay's conception of connection-based equality is discussed. She stresses that regardless the efforts to remove barriers or promote capabilities there will always be people with severe disabilities who are dependent on others and who will not be able to participate as equals. Therefore Kittay proposes a connection-based notion of equality that applies even to the most severely disabled people (and their caregivers). By adopting such a conception of equality they will no longer have to be excluded both from theories of equality and from society. Central to this notion of equality is that everyone's needs have to be taken into account. From Kittay's notion of connection-based equality it can be learned that inclusion also consists of everyone's *needs* being taken into account. This is called the *needs principle*.

The aim of this chapter is to explain the different notions of equality developed by Silvers, Anderson and Kittay in order to make clear what problems they try to solve and which aspects of inclusion play a role in these different notions of equality. This will provide a starting point for the development of an account of inclusion that incorporates all aspects of inclusion these different theories deal with separately.

2.1. Formal Equality

Anita Silvers has developed an account of formal equality based on the presupposition that all people – either with or without disabilities – are equal and should be treated equally.¹³ She observes that in the past, people with disabilities have not been recognized as equal persons with equal entitlements to able-bodied people.¹⁴ This resulted in their exclusion. Formal equality is supposed to ensure that being different from the majority, in itself, does not lead to one's exclusion.

What makes Silvers' argument appealing is that she starts from the idea that it is societies' attitude towards being different from the majority that resulted in the exclusion of people with disabilities, and not the nature of the difference that constitutes a disability. What is required, according to Silvers, to counter act exclusion, is equal treatment. By explaining that equal treatment means being responsive to difference – in order to ensure that people are not being disadvantaged by socially constructed barriers – Silvers employs a convincing argument supporting the inclusion of people with disabilities in society.

¹³ Anita Silvers, "Formal Justice."

¹⁴ *Ibid.*, 55–56.

First, it is described how Silvers bases the legitimacy of claims for formal equality on the commonly shared idea that social arrangements that put certain people in a disadvantaged position are unjust. Subsequently it is explored why Silvers conceives of people with disabilities as facing disadvantages that are rooted in unjust social arrangements. Then it is explained what, according to Silvers, treating people equally comes down to.

After this it is clarified why Silvers conceives of recognition of equality, instead of recognition of difference, as what will improve the position of people with disabilities in society. This is an important point to discuss because it illustrates why Silvers values equality instead of difference. Silvers stresses that it is the recognition of equality that leads toward a more inclusive society. From Silvers's notion of equality it is learned that inclusion requires recognition of one's equality.

Additionally, Silvers' method of historical counterfactualizing is explained in order to show how one can identify unjust past practices of exclusion. This is instructive, because it makes clear that some instances of exclusion do not seem to be problematic in Silvers' terms. Namely, forms of exclusion that result from natural inequalities, as opposed to socially constructed inequalities. Therefore Silvers' account of equality cannot provide the sole basis for an account of inclusion.

According to Silvers, two kinds of inequalities can be distinguished: "artificial inequalities stemming from social arrangements"¹⁵ that occur for instance when "individuals are unwarrantedly penalized because they are identified with an unfairly disparaged group"¹⁶ and "natural inequalities occasioned by individual disparities of talent, industriousness, or luck."¹⁷ Silvers states that artificial inequality is condemned by democratic morality, unlike natural inequality, which is not uniformly rejected by democratic morality.¹⁸

Therefore, according to Silvers, "we must decide whether the disadvantages characteristically associated with those differences we identify as physical, sensory, or

¹⁵ Anita Silvers, "Formal Justice," 15.

¹⁶ *Ibid.*, 15.

¹⁷ *Ibid.*

¹⁸ *Ibid.*

cognitive impairments are artificial or natural.”¹⁹ Because when these disadvantages are artificial there will be hardly any disagreement that society should alter its practices in order to restore the impediment.

Silvers describes how historically people with disabilities had been regarded as deficient and burdensome, and how practices of attending to special needs had led to their segregation from other citizens.²⁰ For example, children with disabilities were sent to special schools and people with disabilities were supposed to travel with special transportation.²¹ She points at a historical development in which people with disabilities were conceived of as unfit to fulfill certain roles such as being an employee or a parent.²²

Citizens with disabilities have also been denied equality with regard to the law. As Silvers explains, people with disabilities “have until very recently been regarded as so naturally inferior as to be ineligible to be equally protected by the law. Their impairments have defeated their appeals to rights, so to speak. Either they have been denied rights others possess because law or tradition deems them incompetent, or else their impairments have barred them from meaningful exercise of the rights others appeal to freely.”²³

According to Silvers, we have to determine whether the disadvantages and unequal treatment people with disabilities face are inseparable from the constitution of their bodies or are due to hostile environments. This will help us decide whether society was justified in treating people with disabilities unequally.²⁴

Silvers emphasizes that, “[o]ften the functional deficits customarily associated with disability are neither more nor less than an alterable cultural artifact.”²⁵ This is expressed in the social model of disability:

The social model of disability transforms the notion of “handicapping condition” from a state of a minority of people, which disadvantages them in

¹⁹ Ibid.

²⁰ Ibid., 24, 25, 117.

²¹ Ibid., 24.

²² Ibid., 54, 55.

²³ Ibid., 55–56.

²⁴ Ibid., 74, 75.

²⁵ Ibid., 75.

society, to a state of society, which disadvantages a minority of people. The social model traces the source of this minority's disadvantage to a hostile environment and treats the dysfunction attendant on (certain kinds of) impairment as artificial and remedial, not neutral and immutable.²⁶

This does not mean that all difficulties people with disability face are socially constructed, but it does mean that most of the time the disadvantages people with disabilities face are not due to their bodies but due to how society treats them. And this is something that can be changed.

As noted above, artificial inequalities stemming from social arrangements should be eliminated. Silvers considers whether the establishment of formal equality for people with disabilities will restore the injustice that resulted in their exclusion throughout history. Formal equality means that people with a disability should be treated equally, according to Silvers, this should be distinguished from treating people similarly.²⁷ “[T]reating people similarly will not be treating them equally in cases in which the actions instrumental to pursuing opportunity are so narrowly or rigidly constrained as to exclude people with (certain) impairments.”²⁸ This means, that a program that can only be accessed by climbing stairs, does not treat people who can and people who cannot climb stairs equally.²⁹ Even though, the door is similarly open to all people, only people who can climb the stairs get entrance.³⁰ The realization of formal equality in this case, does not mean that all people have to be the same, but instead that the built environment should be accommodative to the variety of ways in which people move around in order to provide access to everyone equally.³¹

Getting access should not be a privilege of those who constitute the majority, it should also be provided to people with disabilities who constitute a minority. Equality for Silvers does not mean that all differences between people have to be equalized, but that one should not be disadvantaged by society because of a difference. To ensure this, formal equality should be promoted; every citizen should be recognized as an

²⁶ Ibid.

²⁷ Ibid., 126.

²⁸ Ibid., 127.

²⁹ Ibid.

³⁰ Ibid.

³¹ Ibid.

equal member and thus be treated equally. But, not everyone is convinced that formal equality will be in the interest of people who are part of a marginalized minority. Some feminist are convinced that it is more important to recognize difference in order to improve the position of marginalized groups in society.

2.1.1. *Dilemma of Difference*

Silvers explains that the ones who are seeking justice for historically subordinated groups – such as racial and ethnic minorities, women and people with disabilities – are confronted with dilemmas of difference, which make some of them prefer recognizing difference over equality.³² Silvers refers to Martha Minow³³ as the one who put the dilemma of difference on the agenda.³⁴

The dilemma one faces is the choice between stressing difference – in order to get recognition for the injustices that are connected to particular differences and thereby reinforcing the difference – or not doing so in order to further equality. Equality would be promoted by not emphasizing difference, because when one believes that we are all equal, one should not make distinctions between different groups or kinds of people. But, in our non-ideal world people do face disadvantages because of the fact that they differ from the dominant group. This is for instance the case for women, racial or ethnic minorities and people with disabilities. Not stressing the differences that make these people suffer unjust treatment seems to equal ignoring the problems they face because of it, and thereby disregarding that they should be treated justly. Silvers is very critical about the view that one has to emphasize difference instead of equality. But, as she points out, some feminist did choose difference over equality because:

In the service of equalizing, it is charged, our Enlightenment tradition imposes uniformity on the core descriptions of moral agents, stripping them of their differentiating particularities and positions so that what counts toward moral personhood is neither multifarious nor susceptible of much

³² Anita Silvers, “Reconciling Equality to Difference: Caring (F)or Justice For People With Disabilities,” *Hypatia* 10 (1995) 31.

³³ Martha Minow, *Making All the Difference: Inclusion, Exclusion and American Law* (Ithaca/London: Cornell University Press, 1990).

³⁴ Anita Silvers, “Reconciling Equality to Difference,” 31.

variation. Forms of recognition responsive to race, culture, sex, gender, class, and other features that diversify us thus are dismissed as not vital to moral identity, a repudiation that implicitly confers permission to marginalize individuals for whose personal or social identities these differences are inescapable. Far from liberating members of groups subordinated on account of difference by demonstrating their underlying identity with dominant kinds of persons, the conceptual device of abstracting from difference to uniformity is thought by feminist critics and others to become just another instrument furthering social repression.³⁵

The conception of equality these feminists oppose to is one that discards all differences between people as morally irrelevant, because we are all actually equal. Equality as these feminists describe it, tends to sameness: we are all equal because we are all the same. Of course this does not mean that they conceive of the proponents of equality as believing that people do not differ from each other. But, what they oppose to is the idea that in the morally relevant sense people are all the same – because their differences are considered to be irrelevant – and should thus be treated equally. According to the feminists Silvers refers to, there are differences between people, which are so substantial for the individual, that you cannot abstract these away. Therefore, they prefer difference over equality, because they want recognition for certain differences between people.

But Silvers opposes this stance. According to her, one can reconcile equality to difference and thereby resolve dilemmas of difference. She points out that equality has propelled us “toward progressively inclusive social practice,”³⁶ and therefore worries that letting go of equality also means disregarding inclusion. The way in which Silvers wants to reconcile equality to difference is by considering whether contemporary inequality is due to past practices of exclusion.

2.1.2. Historical Counterfactualizing

By historically counterfactualizing, one can find out whether inequality is due to past practices of exclusion. If one takes the example of public transport, one can ask

³⁵ Anita Silvers, “Reconciling Equality to Difference,” 32.

³⁶ *Ibid.*, 30.

whether public transport would be inaccessible for people who use a wheelchair when the majority of people would use a wheelchair. The answer would be ‘no,’ because the point of public transport is that it is accessible to the public, and if that public consists of wheelchair users, it would be accommodative to wheelchair users. This means that the inequality of access is not due to some difference of the individual who uses the wheelchair, but due to unequal treatment of persons with disabilities. As Silvers points out, people with disabilities have been regarded (or sometimes are still regarded) as unequal due to their bodily or mental differences.³⁷ By pointing out that the established inequalities are not due to these differences, Silvers believes that she can avoid dilemmas of difference by stressing that the difference only contingently caused the inequality. In this way she can be responsive to the difference without reinforcing the inequality by emphasizing the difference, because she transforms the conception of difference in order to promote equality.³⁸

Historical counterfactualizing then strips differentia of their negative meanings by disclosing that the source of adverse signification lies in the remediable accidents of social arrangement, not in the immutable inferiority of the alienated group. By doing so, historical counter-factualizing deflects the regrettable tendency abstract thought has of equivocating between what has been accidentally true of certain kinds of people and what is inescapable about them. It thus counters one of the criticisms levied by advocates of the ethics of difference against the ethics of equality.³⁹

What stands out is that, according to Silvers, the things that distinguish the members of marginalized groups, do not actually make them unequal. Prejudice and maladaptation made people think of disabled people as unequal.

As Silvers points out, a lot of people do believe that disabled people do not have equal moral standing because of their defective bodies.⁴⁰ Therefore, people fail to recognize disabled citizens as equal members of society. “While most other differences between persons are dismissed as contingent and external, and thus as accidental to a

³⁷ Ibid., 34-35, 43-50.

³⁸ Ibid., 50.

³⁹ Ibid.

⁴⁰ Ibid., 34-35.

person's moral being (this being the maneuver of which radical feminist theory complains) disability unmistakably has been embraced as a morally essential attribute, one which assigns those who have it to the borderline of moral worth."⁴¹

Silvers attributes this misconception to an inability of able-bodied persons to understand what it is like to have a disability from the perspective of someone with a disability. The testimony of someone without a disability, about what it is like to have a disability, is not a good source for judging what it actually is like.⁴² Therefore, one should not judge that disabled people are morally inferior to able-bodied people because of such defective testimonies.

What is needed to realize formal equality of people with disabilities seems to be inseparable from inclusion. In order to realize formal equality, one should not be excluded because one differs from the majority. Social practice should be organized in such a way that no one is excluded because of a minority trait. Inclusion requires that everyone is recognized as an equal member of society and is treated equally. As is explained above, recognizing someone as an equal does not mean that one cannot be responsive to differences. Recognizing someone as an equal means that one has to treat the other as an equal as to realize formal equality, this encompasses being responsive to difference. With developing her account of formal equality Silvers emphasizes a very important aspect of inclusion, namely: in order to be included, one has to be recognized as an equal. I will call this the *recognition of equality principle*. When one is recognized as an equal it is no longer contingent whether one is treated equally as to whether one is able to comply with the majority. Even if one is unable to comply with the majority, one will be treated as an equal and not be obstructed by socially constructed barriers that testify of misrecognition of one's equality. This means that one is included, not only because one is not excluded, but also because a stance is taken towards one that encompasses that one belongs as an equal.

By historical counterfactualizing, one can distinguish inequality due to an exclusionary practice, from inequality that is not due to an exclusionary practice. And the latter instances of inequality are not evidently problematic, according to Silvers'

⁴¹ Ibid., 35.

⁴² Ibid., 35-36.

notion of formal equality. This means that not all differences give rise to claims for equality, as will become clear in the following discussion. This may be problematic for the inclusion of people with disabilities, because it could mean that some differences, that encompass a disability, do justify exclusion as is discussed below.

2.1.3. Problems with Formal Equality, Historical Counterfactualizing and Inclusion

To find out whether one is unjustly excluded one can counterfactualize what a certain practice would look like when the minority trait prevails. This leaves open the possibility that the traits typical for certain minorities do justify exclusion because one cannot imagine how a certain practice would be different when the majority had those features. For example, what would a concert be like when the majority of the people were hypersensitive to sound? Probably there would be no concerts.⁴³ It seems counter intuitive to say that equality requires us to no longer have concerts because there are people who suffer from the sound of music. Maybe this issue rises because the counterfactualizing is done in the wrong way. Perhaps one should not ask how a concert would be organized when the majority of the people were hypersensitive, but how society would organize the performance of music. This would probably only be done at particular places where people who cannot bear it do not have to be. For example, there can be music at the concert hall, but not at the community home. This does mean that hypersensitive people may be excluded from the concert hall, because of their sensitivity, by the practice of playing (loud) music. Would this mean that hypersensitivity is a difference that legitimizes exclusion? And does that open the door for excluding people with disabilities?

On the one hand, Silvers seems to advocate that equality means that differences such as disability are morally irrelevant and that therefore people should not be excluded because of a disability. On the other hand, she does leave the possibility for exclusion based on disability open. What Silvers wants to achieve with historical counterfactualizing, is leveling the playing field in order to make sure that people with disabilities do not face artificial obstacles that result in their exclusion.⁴⁴ She is aware

⁴³ As it does not make sense to organize concerts without music.

⁴⁴ Anita Silvers, "Formal Justice," 136.

that a level playing field possibly may not result in the inclusion of all persons with a disability.⁴⁵

But for Silvers this should not result in concluding that people with disabilities are therefore unequal and that treating them equally is based on a fiction. Silvers rejects such a view when she discusses the work of Charles Taylor who employs such an argument.

By assuming that being handicapped places an individual in global deficit, Taylor suggests that it is only in virtue of an intervening fiction that such "defective" agents have equitable access to the categorical principles on which humans generally are accorded dignity or respect. Far from flattering the egalitarian project, this way of putting things deconstructs it by intimating that "handicapped" people are equal only by extension or derivation or fiction because they really don't possess the essentially humanizing capacity to fulfill their potential 'normally.'⁴⁶

Silvers objects to Taylor by stressing that fulfilling one's potential cannot be the requirement for normalcy or equality because lots of people do not fulfill their potential.⁴⁷ What she wants to point out, when she tries to reconcile the equality of disabled people to their differences, is that these differences do not legitimize unequal treatment, and that the formal equality of people with disabilities should not be considered as based on some kind of fiction. Unfortunately, she does not elaborate on the cases in which someone with a disability is excluded and historical counterfactualizing cannot point at a historical development that has led to this exclusion.

Silvers does propose equal treatment instead of compensatory treatment in such a way that she allows for the situation where not all disabled are included in all common practices.⁴⁸ In her view, there is a strong connection between equality and exclusion, but furthering equality for her does not equal ensuring inclusion for all persons with a disability. Formal equality, as proposed by Silvers, aims at abolishing

⁴⁵ Ibid., 135.

⁴⁶ Anita Silvers, "Reconciling Equality to Difference," 35.

⁴⁷ Ibid.

⁴⁸ Anita Silvers, "Formal Justice," 138.

inequalities that result from historical exclusion of people with disabilities. This is important for people with disabilities, who are capable of participating, but who have been excluded, because they were not recognized as equal and thus were not treated equally. By providing them with equal rights and access, they are able to take care of themselves and participate in society. Inclusion, following Silvers' notion of formal equality, has to do with being recognized as equal members of society and thus being treated equally.

But, some people with disabilities are still unable to participate in common practice in society when all the socially constructed barriers are eliminated. Their exclusion consists of more than misrecognition of their status as an equal member of society. Realizing formal equality does not lead to their inclusion in society. Thus in order to be included something more is needed than recognition of one's equality. Silvers' account of formal equality is unfit for guiding the improvement of the position of people with disabilities in society who are in need of support and aids in order to be included in society. Attention should be paid as to what inclusion means for these people with disabilities. It cannot be the case that it is justified to exclude people who cannot function on their own from society.

Formal equality does not give these people a claim for justice to get the support they need in order to get equal standing as a citizen. This is taken up by Elisabeth Anderson who develops an account of equality that includes the claims for justice of people who need more than just a level playing field in order to be able to participate as equal citizens in society.

2.2. Democratic Equality

According to Elisabeth Anderson, the point of equality is standing in relationships of equality to others.⁴⁹ This is, according to her, what is important about equality from the perspective of marginalized groups like women, gay people, and people with disabilities.⁵⁰ She agrees with Silvers that equality is not about compensating people for bad luck.⁵¹ But, according to Anderson, the point of equality

⁴⁹ Elisabeth S. Anderson, "What Is the Point of Equality?" *Ethics* 109 (1999) 289.

⁵⁰ *Ibid.*, 312–315.

⁵¹ *Ibid.* 288.

is not being treated equally, but having equality in social relations.⁵² She points out that egalitarian political movements oppose to “basing social order on a hierarchy of human beings, ranked according to intrinsic worth.”⁵³ They base their claims of social and political equality on the fact that all people have equal moral worth.⁵⁴

In this section Anderson’s notion of democratic equality is explained. For Anderson equality does not only require a level playing field but it also requires promoting capabilities necessary for participation. With this Anderson fills in the gap that Silvers left with regard to people with disabilities who are unable to take part in common practice when only provided a level playing field. Anderson argues that equality entails that these people get the support and aids they need in order to be able to participate. In order to be included as an equal citizen one has to be able to participate as an equal in society. Anderson’s discussion brings to the front that being involved in participation is an important aspect of inclusion. People who are unable to participate should get the support they need to obtain the required capabilities. By focusing on enabling participation, Anderson’s argument supports the inclusion of people with disabilities who, with Silvers, were not included in common practice.

But focusing on participation seems to be incompatible with the inclusion of people with such severe disabilities who, regardless of the support they get, will not be able to participate. Anderson seems to be unable to resolve this because participation plays such a central part in her notion of equality.

Anderson’s notion of democratic equality is a relational account of equality. According to this account two people are “equal when each accepts the obligation to justify their actions by principles acceptable to the other, and in which they take mutual consultation, reciprocation, and recognition for granted.”⁵⁵ It “aims to abolish socially created oppression.”⁵⁶ But it also tries to integrate matters of equal recognition

⁵² Ibid., 287–337.

⁵³ Ibid., 312.

⁵⁴ Ibid., 313.

⁵⁵ Ibid.

⁵⁶ Ibid.

with equal distribution of goods.⁵⁷ What stands out is that this notion of equality tells us something about how people should relate to each other, namely as equals.

From this conception of equality Anderson derives principles of justice. In order to get a better understanding of what democratic equality means it is useful to have a closer look at what these principles of justice are. These principles are based on the idea that the state (as citizens acting collectively) should secure the social conditions of everyone's freedom.⁵⁸ And "that the social condition of living a free life is that one stand in relations of equality with others."⁵⁹ Anderson explains the connection between freedom and equality as follows:

Equals are not subject to arbitrary violence or physical coercion by others. Choice unconstrained by arbitrary physical coercion is one of the fundamental conditions of freedom. Equals are not marginalized by others. They are therefore free to participate in politics and the major institutions of civil society. Equals are not dominated by others; they do not live at the mercy of others' wills. This means that they govern their lives by their own wills, which is freedom. Equals are not exploited by others. This means they are free to secure the fair value of their labor. Equals are not subject to cultural imperialism: they are free to practice their own culture, subject to the constraint of respecting everyone else. To live in an egalitarian community, then, is to be free from oppression to participate in and enjoy the goods of society, and to participate in democratic self-government.⁶⁰

Thus what it means to be equals encapsulates what is required to be free. And as "[e]quals are not marginalized," meaning that they are not put aside and excluded from participation, inclusion is part of what equality consists of. What justice requires then, is what is needed to stand in an equal relationship with others. As we will see, this also means that the inclusion of all citizens in certain practices should be ensured. Inclusion has to do with participation.

⁵⁷ Ibid., 314.

⁵⁸ Ibid.

⁵⁹ Ibid., 315.

⁶⁰ Ibid.

According to Anderson the preconditions of justice are best explained with the help of Amartya Sen's capabilities approach.⁶¹ Anderson formulates the egalitarian requirements in terms of capabilities both negative and positive. "Negatively, people are entitled to whatever capabilities are necessary to enable them to avoid or escape entanglement in oppressive social relationships. Positively, they are entitled to the capabilities necessary for functioning as an equal citizen in a democratic state."⁶²

The capabilities considered necessary for functioning as an equal citizen in a democratic state can be divided in three categories. One should be capable of functioning "as a human being, as a participant in a system of cooperative production, and as a citizen of a democratic state."⁶³ As Anderson describes it:

To be capable of functioning as a human being requires effective access to the means of sustaining one's biological existence—food, shelter, clothing, medical care—and access to the basic conditions of human agency—knowledge of one's circumstances and options, the ability to deliberate about means and ends, the psychological conditions of autonomy, including the self-confidence to think and judge for oneself, freedom of thought and movement. To be capable of functioning as an equal participant in a system of cooperative production requires effective access to the means of production, access to the education needed to develop one's talents, freedom of occupational choice, the right to make contracts and enter into cooperative agreements with others, the right to receive fair value for one's labor, and recognition by others of one's productive contributions. To be capable of functioning as a citizen requires rights to political participation, such as freedom of speech and the franchise, and also effective access to the goods and relationships of civil society. This entails freedom of association, access to public spaces such as roads, parks, and public accommodations including public transportation, the postal service, and telecommunications. This also entails the social conditions of being accepted by others, such as the ability to appear in public without shame, and not being ascribed outcast status. The freedom to form relationships in civil society also requires

⁶¹ Ibid., 316.

⁶² Ibid.

⁶³ Ibid., 317.

effective access to private spaces, since many such relationships can only function when protected from the scrutiny and intrusions of others. Homelessness—that is, having only public dwelling—is a condition of profound unfreedom.⁶⁴

Equality for Anderson thus requires that everyone has the capabilities that are necessary for functioning as an equal citizen. To summarize, according to Anderson, all citizens have equal moral worth, therefore they should stand in relationships of equality with each other. In order to relate to each other as equals every citizen should be able to function as an equal citizen. This requires that one has the capabilities that enable this.

As Anderson points out, the claims of disability rights activist, for example accessibility of public space or adaptation of working environment, can be understood in terms of these capabilities necessary for functioning as equal citizens.⁶⁵ The notion of democratic equality can be used to diagnose exclusion as a form of injustice. An example that Anderson gives is that people may not be excluded from civil society based on a disability.⁶⁶ As she explains, someone who is unable to walk is therefore entitled to a wheelchair and ramps that provide access to public buildings. Such aids and adjustments prevent that one is excluded from participating in society because of a particular disability. Moreover, according to Anderson, civil society should be adjusted as to include people with disabilities because “individuals need to be able to move around civil society to have equal standing as citizens.”⁶⁷

For Anderson, inclusion in participation is part of equality. One needs to be included in order to have equal standing as a citizen. Interestingly, Anderson allows for unequal treatment or unequal distribution of resources in order to promote equality. The person unable to walk gets a wheelchair, and the person who is able to walk doesn't get a wheelchair or something equally expensive, as would be expected when equality is viewed as distributing resources equally among people. The unequal treatment is legitimate as it results in equality in the relational sense because both will

⁶⁴ Ibid., 318.

⁶⁵ Ibid., 320.

⁶⁶ Ibid., 331.

⁶⁷ Ibid.

be able to move around and participate as equals.

This account of equality thus opposes an account of equality that prescribes that resources should be distributed equally among all citizens regardless of one's needs or merits. Such accounts are insensitive to individual differences in ability between citizens. Anderson's account of democratic equality clearly is sensitive to such differences and she tries to neutralize the impact of such differences on one's ability to function as an equal citizen. She is aware of the fact that standing in a relation of equality to each other in practice requires more than the presupposition that everyone has equal moral worth. It requires that everyone is able to participate as an equal citizen.

For Anderson, equality (for people with disabilities) means not only that society may not hamper one's functioning by installing or maintaining obstacles that would not have been there were the disability a majority trait (as Silvers states). But it also means that measures should be taken to include the ones who, even without any environmental obstacle, would not be able to participate. It thus goes a step further than what Silvers' account of equality allows for. Democratic equality for people with disabilities means that they should get the support they need in order to acquire the capabilities necessary for participating as equal citizens. In this way people with disabilities and people without disabilities can stand in a relation of equality with each other in society.

Following Anderson's theory, the focus of inclusion lies with participation. In order to be included as an equal citizen one has to be able to participate. I will call this the *participation principle* (this principle will be formulated more precisely in the following chapter). Although Anderson gives strong arguments why people should be included in participation in order to be included in society as equals, from her discussion it cannot be concluded yet that participation is what inclusion, in more general terms, consists of. In the next chapter it is explained that participation is one of the requirements of inclusion more generally. In order to be included people should not be excluded from participation. The relationship between participation and inclusion will be further explained in the next chapter. In the final part of this section I will explain why Anderson's focus on participation also has a downside.

Anderson's argument says that one can only be included as an equal when one is able to participate as an equal in society. But some people with disabilities will never be able to participate as equals in society because, as Kittay points out, the nature of their disabilities makes it impossible to acquire the capabilities needed in order to participate as an equal citizen.⁶⁸ This means that these people do not get standing as equal citizens. Democratic equality does not tell us how to include these people as equals in society. It seems as if the inability to enable these people to participate makes their inclusion impossible. This would make people with severe disabilities a necessarily marginalized group. But this is in tension with the equal moral worth of all people that forms the foundation of Anderson's theory. Anderson thus is not able to explain how all people (with disabilities) can be included in society. As did Silvers' theory, also Anderson's theory leaves some people out of consideration although they are considered, by both authors, to be of equal moral worth with other citizens.

In order to find out what is required to include people with very severe disabilities, in the next section, Kittay's notion of connection-based equality is discussed. She develops an account of equality that is supposed to also include people with very severe disabilities as equals.

2.3. Equality and Dependency

For some people, reaching the level of capabilities that is necessary for functioning as an equal citizen is impossible. In *Love's Labor*,⁶⁹ Kittay describes her own daughter, Sesha, who is disabled and whose cognitive and physical condition will not allow her to function as an equal citizen as described by Anderson. Sesha is unable to speak or express herself with words, probably both because of her physical and mental condition. She cannot move around independently and it is questionable whether she can reason. She cannot even feed herself adequately. For her, being capable of functioning as an equal participant in a system of cooperative production or functioning as a citizen, as described by Anderson above, seems impossible regardless of the support she gets. This means that Sesha will not be an equal in Anderson's terms and thus that one cannot make claims for justice for Sesha based on her

⁶⁸ Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (New York: Routledge, 1999) 172-173.

⁶⁹ *Ibid.*, 147-160.

equality. There seems to be a tension between stating that all persons have equal moral worth and not being able to include all persons equally within one's theoretical framework. According to Kittay, theories “which do not consider dependency at their heart may be based on the concept of persons as moral equals, but they will result in a society in which the claim to equal moral worth cannot be realised for *all*.”⁷⁰

Kittay explains why dependency should play a central role in a theory that seeks justice for all. As she points out, it is not only central to the lives of some people with disabilities, it is something that we all experience at some points in our lives.⁷¹ Inevitably, we are dependent from the moment we are born until we reach maturity and after that we can again face periods of dependence due to illness, accidents or old age. We are also likely at some point in our lives to get involved with dependency as we take care for our dependant children, parents, partner or friends. Even as a professional, dependency can play a major role, for example, when you work as a nurse or at a day-care centre.

Because dependency strongly affects our status as equal citizens (that is, as persons who, as equals share benefits and burdens of social cooperation), and because it affects all of us at one time or another, it is not an issue that can be set aside, much less avoided. Its consequences for social organization cannot be deferred until other traditional questions about the structure of society have been settled without distorting the character of a just social order. Dependency must be faced from the beginning of any project in egalitarian theory that hopes to include *all* persons within its scope.⁷²

According to Kittay we need a connection-based notion of equality in order to include people who are dependent and the ones who take care of the dependants into our notion of equality.⁷³ Kittay finds the basis for such a notion of equality in the phrase “We are all *–equally–* some mother’s child.”⁷⁴ She does not want to take the mother-child relation exclusively as the basis for the connection-based notion of

⁷⁰ Ibid., 77.

⁷¹ Ibid., 29, 77.

⁷² Ibid., 77.

⁷³ Ibid., 28.

⁷⁴ Ibid., 25.

equally.⁷⁵ For Kittay it is about the connection that is a fundamental condition for human survival. She explains this as follows:

That nothing can fully alienate the responsibility of others to recognize us as some mother's child resides in that feature of human existence that demands connection as a fundamental condition for human survival. No one can survive and become a member of the human community without the interest of some mothering person(s) who has provided a degree of preservative love, a concern in fostering the individual's growth, and a training for social acceptability. When we respect an individual as some mother's child, we honor the efforts of that mothering person and symbolically of all mothering persons. When we do not, not only are rights belonging to the abused individual violated, but the efforts of the mothering person are dishonoured. The sanctity of the relation that makes possible all human connection is violated.⁷⁶

The question central to connection-based equality is: "What are my responsibilities to others with whom I stand in specific relations and what are the responsibilities of others to me, so that I can be well cared for and have my needs addressed even as I care for and respond to the needs of those who depend on me?"⁷⁷ Connection-based equality also takes nested dependencies into account, for example a mother caring for her new born child may not be able to take care of herself by doing groceries or cooking meals, or providing money. Therefore the task of taking care of the mother has to be taken up by someone else. Connection-based equality "insists that our full functioning presumes our need for and ability to participate in relationships of dependency without sacrificing the needs of dependents or dependency workers."⁷⁸ With the help of connection-based equality one can make claims for justice aimed at the welfare both of the dependent and the one taking care of the dependend. Kittay focuses much on the needs of the one (mostly women) taking care of someone with a severe disability. Although I do agree with Kittay that

⁷⁵ Ibid., 26.

⁷⁶ Ibid., 69.

⁷⁷ Ibid., 28.

⁷⁸ Ibid., 132.

the concerns of the ones taking care of others are not getting as much attention as they should, this to a large extent exceeds the scope of this thesis. Therefore, in what follows I will focus on what connection-based equality means for persons with disabilities.

Connection-based equality puts the needs people have and their dependency on others at the heart of inclusion. Only when we incorporate the notions of need and dependency can we develop a theoretical framework that includes all people.

Because connection-based equality does not take any characteristic of an individual as the basis for equality no one is excluded from being equal. This means that regardless of the nature of one's disability one will always be included as an equal and one's equality will be a reason for claims of justice. So even if one is extremely limited in both one's cognitive and physical abilities one still counts as an equal based on one's connection to others.

But even though Kittay gives a central place to the connections that exist between people with regard to dependency she does not want to let go of the liberal conception of a citizen as a “free, independent, equal individual to whom rights attach.”⁷⁹ This citizen, according to Kittay, does not only have the two moral powers Rawls mentions – “an ability to form and revise one's conception of one's own good and a sense of justice”⁸⁰ – but also a third one, namely “the capacity for responding to those in need with care.”⁸¹ What follows from this, according to Kittay, is that:

If we possess basic liberties, freedom of movement and choice of occupation, and have access to the powers and prerogatives of public office, as well as income and wealth, then we can be said to possess the political and civil rights of citizenship. But full social citizenship requires that if we are called upon to care, we can fulfil these duties without losing our ability to care for ourselves, and that in caring for another, the full burden of support as well as care for the one dependent on us will not fall upon our shoulders

⁷⁹ Ibid., 131.

⁸⁰ Ibid.

⁸¹ Ibid.

alone. Without such assurance, we have not yet attained the powers and capacities to function as free and equal citizens.⁸²

Unfortunately, Kittay does not explain what citizenship means for people with such severe disabilities that they are unable to attain the powers and capacities needed to enact the three moral powers and the associated rights. Kittay only focuses on the caretaker in her proposals for a just society. Still, by virtue of being “some mother’s child” the needs of even the most severely disabled people should be cared for.

It is unclear whether Kittay intends to extend her theory of justice to the ones who are dependent. Her major concern seems to be the ones who do the caring. As did Anderson, Kittay proposes a capabilities approach as a theory of justice.⁸³ She does not give an extensive account of which capabilities should be promoted, besides the capability to care for someone in need. But one can expect that these capabilities should be promoted for people with disabilities as well. The advantage, for people with very severe disabilities who cannot acquire important capabilities, of this approach is that the care provided to them by others is taken into account. Everyone’s needs are taken into account by the notion of connection-based equality. In order to realize inclusion for even the most severely disabled people it is important that: one’s needs are taken into account. This I will call the *needs principle*. Kittay did make clear how taking needs into account is of importance for a theory that includes everyone as an equal. In the following chapter the *needs principle* as a requirement of inclusion will be further explained.

Kittay does not exclusively comprehend connection-based equality as a basis for justice, still in what follows it is discussed what the disadvantage of connection-based equality is for people with disabilities. By focusing on addressing needs, instead of focussing on being recognized as an equal in order to be treated as an equal or standing in relationships of equality to others by being included in participation, it is likely that these important aspects of equality are neglected. For people with disabilities who are conceived of as being non-productive and depend on others,

⁸² Ibid.

⁸³ Ibid., 131-132.

but who are actually able to participate, connection-based equality as addressing needs may not have the empowering effect of formal and democratic equality. Although people with disabilities will be included as equals whose needs should be attended, their connection-based equality does not promote their inclusion in participation or their recognition as equals who should be treated equally in Silvers' sense. It also does not do much work with regard to counteracting the stigma of being non-productive and dependent. Actually, focusing on needs of people with disabilities can be interpreted as focussing on difference instead of equality, which is exactly what Silvers objected to. On the other hand, considering people's needs may actually stress their equality as Kittay explained in the above. People with and without disabilities may have the same needs. What might differ is the amount of help or care they need to meet those needs. So, it may not be focusing on needs Silvers opposes to, but just focusing on care.

2.4. Conclusion

Thus far we have identified three principles of inclusion with the help of the three different theories of equality: the *recognition of equality principle*, the *participation principle* and the *needs principle*. The core values of these three different accounts of equality all have to do with promoting inclusion as is shown in this chapter. It is suggested that the moral equality of all humans forms the basis for the inclusion of all people (with or without disabilities) in society. Silvers, Anderson and Kittay all have provided a firm justificatory basis for different ways in which our equality is of concern to society.

According to Silvers, the equality of all people makes that they should be recognized as such, which takes shape in treating them equally and granting them equal rights. People should not be obstructed by socially constructed barriers, that testify of their misrecognition as equals, even though they are part of a minority such as people with disabilities. In order to be included one has to be recognized as an equal (*recognition of equality principle*).

Anderson argued that equality has to take shape in the relations in which people stand to each other. People have to be able to participate as equals in order to stand in a relation of equality to others. Therefore, the capabilities necessary for participation have to be promoted by society. In order to be included people should be involved in participation (*participation principle*).

Kittay pointed out that only if one is responsive to needs and dependence one can have a theory of equality that incorporates all people, even the ones with very severe disabilities, as equals. Meeting people's needs has to be of concern for society in order to include all people as equals. In order to be included one's needs have to be taken into account (*needs principle*).

As is discussed above, if one only follows the *recognition of equality principle*, people with disabilities who need more than equal rights and a level playing field in order to be included in society are left out of consideration. The *participation principle* fills in the gap the recognition principle leaves in this regard by emphasising the importance of participation and thus also the promotion of participation. Still, if one only follows these two principles, people who are unable to participate, regardless of a level playing field and the support they receive, are still not included. The *needs principle* provides a basis on which even the most severely disabled people can be included in society, although it is not able to promote inclusion in the sense of the other two principles.

If one unites these three principles, one gets an account of inclusion that has the advantages of all three kinds of equality without their shortcomings. By developing such an account of inclusion based on these notions of equality one has a firm ground for diagnosing unjust exclusionary practices and a powerful guideline for what kind of changes in society will lead towards the inclusion of all citizens. Equality forms the basis: we are of equal moral worth, and therefore we should all be included. The aim of the following chapters is to give substance to what inclusion means.

In the next chapter, more is said about the content of the three principles of inclusion. It is explained that the *recognition of equality principle* and the *participation*

principle are connected. Therefore participation is an essential aspect of inclusion. It is explained that the *participation principle* is compatible with the inclusion of people who are not able to participate.

3. The Requirements of Inclusion

In the previous chapter three principles of inclusion were identified. In this chapter it is explained how these principles can be unified into one account of inclusion. It already became clear that the *recognition of equality principle* and the *needs principle* are substantial to inclusion. Why participation is essential to inclusion (if one is not concerned with including people as equals in society) did not get attention yet. Therefore, with the help of Nancy Fraser's notion of parity of participation, it is argued that participation as a peer is connected to recognition of the other as an equal. This connection makes it problematic to say that one is recognized as an equal if one at the same time is not included in participation as a peer. Therefore, participation as a peer is part of inclusion.

However, this leaves us with the problem identified in the former chapter, how can one include people with severe disabilities who are unable to participate as peers. It is argued that it is possible to include people who are unable to participate as peers even when one sticks to the *participation principle* as one of the requirements of inclusion.

Furthermore, the content of the *recognition of equality principle* and the *needs principle* as requirements of inclusion is explained more extensively.

3.1. Participation as a Norm for Justice and Recognition

Nancy Fraser explains the importance of participation.⁸⁴ This has to do with her conception of recognition, the so-called *status model*. Fraser treats recognition "as a question of social status."⁸⁵ "[W]hat requires recognition is not group-specific identity but rather the status of group members as full partners in social interaction."⁸⁶ Misrecognition for Fraser means: "*social subordination* in the sense of being prevented from *participating as a peer* in social life."⁸⁷ She uses the notion of participating as a peer as a means to evaluate the justice of social practices.

⁸⁴ Nancy Fraser, "Recognition without Ethics?" *Theory, Culture & Society* 18 (2001) 21–42.

⁸⁵ *Ibid.*, 24.

⁸⁶ *Ibid.*

⁸⁷ *Ibid.*

To view recognition as a matter of status is to examine institutionalized patterns of cultural value for their effects on the relative standing of social actors. If and when such patterns constitute actors as *peers*, capable of participating on a par with one another in social life, then we can speak of *reciprocal recognition* and *status equality*. When, in contrast, institutionalized patterns of cultural value constitute some actors as inferior, excluded, wholly other or simply invisible, hence as less than full partners in social interaction, then we should speak of *misrecognition* and *status subordination*.⁸⁸

Parity of participation functions for Fraser as a standard against which one can measure whether claims for recognition are morally justified.⁸⁹ If one makes a claim for recognition, one should be able to affirm that institutionalized patterns of cultural value currently deny one the opportunity to participate on a par with others.⁹⁰ If one is not denied the opportunity to participate by institutionalized patterns of cultural value one cannot make a justified claim for recognition. Furthermore, Fraser argues that parity of participation can also be used as a standard for determining whether a claim for distributive justice is warranted. For parity of participation to be possible “the distribution of material resources must be such as to ensure participants’ independence and voice.”⁹¹ Inequalities in material resources that impede parity of participation are unjust.

From this account of recognition and participation we can learn that being able to participate is important in order to be recognized and to have equal status. The norm of parity of participation comprehends two universalist claims: “[f]irst, it encompasses all (adult) partners to interaction. And, second, it presupposes the equal moral worth of human beings.”⁹² But this does not mean that Fraser only allows for claims for

⁸⁸ Ibid.

⁸⁹ Ibid., 31.

⁹⁰ Ibid., 32-33.

⁹¹ Ibid., 29.

⁹² Ibid., 30.

recognition that result from practices in which the common humanity of some participants is denied.⁹³

Fraser does acknowledge that misrecognition can also involve “denying some participant’s distinctiveness.”⁹⁴ And in such cases “the remedy could be recognition of specificity.”⁹⁵ Hereby the notion of parity of participation is consistent with Anita Silvers’ notion of formal equality because both emphasize that one should be responsive to differences between people in order to be able to treat them equal. The *recognition of equality principle* fits well with Fraser’s notion of status equality. Her analysis of recognition as status equality can thus be applied to the *recognition of equality principle* as well.

The notion of parity of participation also much resembles Elizabeth Anderson’s notion of democratic equality, in which being able to participate as an equal citizen was the central requirement. As with Anderson’s democratic equality, parity of participation leaves room for recognizing differences that may affect one’s ability to participate. Both authors emphasize that justice should be based on the relations in which people stand to each other. Anderson argued that certain capabilities should be promoted in order to be able to function as an equal citizen and thus to stand in an relationship of equality with others. Fraser does not make explicit what, according to her, the requirements of participation are, in terms of, for example, capabilities, but she does recognize that the distribution of material resources influences one’s ability to participate as a peer. From Anderson’s notion of democratic equality the *participation principle* as a requirement of inclusion was derived, stating that in order to be included one should be involved in participation. This principle should be extended considering the above discussion about parity of participation in order to display the specific kind of participation that is connected to recognition of one’s equality. In order to be included one should be involved in participation as a peer.

From Fraser’s account of parity of participation it follows that there is a very tight connection between participation and recognition. According to Fraser participation as a peer can serve as a standard for determining whether one is recognized as an

⁹³ Ibid.

⁹⁴ Ibid.

⁹⁵ Ibid.

equal member of society. This means that recognition without parity of participation seems to be inconsistent because it is parity of participation that testifies of reciprocal recognition. Therefore a notion of inclusion with recognition and without participation seems to lack something very important.

Joel Anderson further explains the interrelatedness of participation and recognition.⁹⁶ He points out that in order to participate it is not enough that one has the required skills and interest in taking part in a particular activity. “The other participants must, at some level, also acknowledge one to be a co-participant.”⁹⁷ He illustrates this as follows: “I can kick around a football on a pitch where a game is being played, but unless I’m considered to be a co-participant, I’m not one.”⁹⁸ This exemplifies not only that participation is important for recognition, but also that recognition is essential to participation.

But inclusion does not necessarily entail participation and, as is argued, one can be included in an activity without participating. This certainly needs some elaboration in order to make clear what is meant by inclusion (without participation).

3.2. Three Principles of Inclusion

It is clear that the participation principle is part of inclusion, so now an account of inclusion based on the three principles can be formulated.

Inclusion is about a state one is in, a state brought about by others. Being included means being part of a group. In order to be part of a group some requirements have to be met, and these have to be met by others. This makes inclusion relational; one cannot be included if others do not comply with one’s inclusion. For A to be included in a group consisting of B and C, B and C have to include A. Inclusion thus is a state that can only be brought about by others.

The three principles of inclusion thus far identified give content to what being included comes down to. Together they form the requirements of inclusion. To better

⁹⁶ Joel Anderson, “Intercultural Dialogue and Free, Full and Equal Participation: Towards a new agenda for an intercultural Europe,” in *Intercultural Dialogue: Enabling free, full and equal participation*, 4–34 (London: Platform for Intercultural Europe Discussion, Alliance Publishing Trust, 2010) 14.

⁹⁷ Ibid.

⁹⁸ Ibid.

fit the relational character of inclusion the principles will be formulated in a slightly different way than has been done above.

One is included if:

1. One is recognized as an equal member of the group, by the group.
(*Recognition of equality principle*).
2. One is not excluded from participation as a peer, by the group.
(*Participation principle*).
3. The individual needs one has are taken into account by the group.
(*Needs principle*).

Inclusion requires that each of these three requirements be met. In what follows it will be explained what fulfilling these principles comes down to. As was pointed out earlier, the *participation principle* might not be compatible with the inclusion of people with such severe disabilities that they are unable to participate as peers. It will be explained why it is still possible to include these people, regardless of the *participation principle*.

3.2.1. Recognition principle

The first principle distinguishes inclusion from being conceived of as being part of a group based on some predicate that applies to the person, such as being a female, being a student or being an American. It tells us that whether or not one is being included depends on whether the other members of a group recognize one as an equal member of the group. This recognition of one's equality takes shape in the realization of formal equality as explained in the former chapter. This does not only mean that one is granted equal rights to others, it also means that others do not install or maintain socially constructed barriers that result in one being treated unequally.

3.2.2. Participation principle

The second principle tells us that people should not be excluded from participating as a peer by other members. This does not only mean that others should not reject one as a participant, but it also incorporates that the capabilities necessary for participation should (if needed) be promoted by others. In order for this principle to be compatible with the inclusion of people with severe disabilities in society it is necessary to uncouple participation from inclusion. This seems to contradict the argument of Fraser about the connection between recognition and equality. I will argue that it is possible to include someone by recognizing his equality and taking his needs into account without that person being able to participate as a peer.

In what follows I do not argue that it is legitimate to deny someone with a disability who is – with or without any support – able to participate as a peer the opportunity to participate as a peer. This would be unjust and in conflict with recognizing that person as an equal member of society. And I do not allow for this possibility because that would imply that all persons can be included in society, even though all persons with disabilities are denied participation. This is highly controversial as it is for instance in conflict with the *Convention on the Rights of Persons with Disabilities* (CRPD), which demands the promotion of participation of people with disabilities. As Joel Anderson emphasises, the importance of participation is recognized by several UN conventions and declaration.⁹⁹ In article 3 of the CRPD it is stressed that one of the general principles of the convention is “[f]ull and effective participation and inclusion in society”¹⁰⁰ of people with disabilities. That participation of people with disabilities is something one should strive for is assumed throughout the CRPD. Not only in article 3 but also in the articles 19, on living independently and being included in the community, 24, on education, 26, on habilitation and rehabilitation, 29, on participation in political and public life and 30, on participation in cultural life, recreation, leisure and sport, furthering and ensuring participation of people with disabilities in different practices in society is put forward.¹⁰¹ Participation as a norm for the fair treatment of people with disabilities thus is widely recognized.

With the help of two examples I will show that when one is not excluded from participating as a peer by others, one can be included without being able to

⁹⁹ Ibid.

¹⁰⁰ UN Convention on the Rights of Persons with Disabilities.

¹⁰¹ Ibid.

participate. This makes my account of inclusion compatible with the inclusion of people with severe disabilities.

Take the case of Billy, a boy in a wheelchair who loves football. His able-bodied friends also love football and in the weekends they play football at the local sports club. This could be a very sad story in which Billy spends his weekends without his friends, watching television and regretting that he could not participate. But it can also be one about how Billy is included in the sports club, even though he is not able to play football. Billy actually joins his friend every weekend, having fun with them in the dressing room before the game, joining them to the sports field, shouting directions from the sideline and after the game he celebrates the victories and mourns the defeats together with the players. Billy is included in the football club without being able to participate. The players of the team recognize him as part of the group and his needs are taken into account. When they have a game out of town they make sure that Billy can come with them in the bus and when the community office wanted to move the club out of their accommodation to a new sports center that was not wheelchair accessible they organized a petition against it.

Two objections can be made against the case of Billy. First, one can argue that Billy does participate in the sports club, although not in the actual football game, he does participate in the sports club because he joins all the activities. Second, one can argue that the sports club, in order to be inclusive, should play a game in which Billy can participate, such as basketball. I do agree with the first objection, Billy, does participate in such a substantial part of the activities that it seems to be only a minor issue that he does not play football. Being part of the football club seems to consist of much more than playing football. For example, the coach is also part of the team without playing matches. Still, one can argue that playing football plays a crucial role in being part of the football team. The coach and the players do contribute to the realization of a football game and Billy does not. Therefore, he does not participate in the core activity of the football club, namely playing football. This makes the example count as an example of Billy being included but not participating (in the core activity).

The second objection I disagree with. Of course, the members of the football club may decide to do a different sport that Billy can play as well. But, that would mean

that there no longer is a football club, but instead there is a basketball club.¹⁰² It would be paradoxical if, in order to be included in a football club, the football club would have to stop being a football club. However, the following example gives a stronger version of someone being included without being able to participate.

Peter is included in the team of employees at the supermarket. Peter has Down syndrome and he has problems with concentrating on a job. Although he is at the supermarket to stock shelves, or at least to assist with stocking shelves, most of the time he is just strolling the isles or having a smoke together with the employees who take a break. Peter works at the supermarket on a voluntary basis and he is not productive. Every job he starts has to be finished by a colleague, and one of his colleagues has to take time to motivate him to start working. It is clear that Peter is not participating as an employee in the supermarket, and it does not make sense to say he participates in the supermarket simply because he is there. The customers are also present at the supermarket, but are not participating as employees. Let us assume that everything has been done to improve Peter's position in the supermarket, to enable him to actively participate, but that it did not work out. However, one can speak of Peter being included in the supermarket staff; the other employees recognize him as part of the team, he gets a uniform, and with Christmas, when all employees get a present from the company, he gets one as well. Also, his needs are taken into account; he is provided a quiet place to eat his lunch, his colleagues pay attention to him, they make sure that he does not feel lonely and when around Easter it is too busy in the supermarket to give him any attention, the staff let him and his parents know in advance so he can decide to take some days off.

But, one should note that inclusion without participation as a peer is the exception rather than the rule. In the case of Peter it is possible to include him without him being able to participate because, regardless the effort taken, he is not able to participate. His inability to participate does not result from his colleagues not recognizing him as an equal. They do recognize him as an equal member, as testifies the way they take him up in the team as a member of the employees. Peter's disability prevents him from participating as a peer in the work that takes place at the

¹⁰² One can also say that there continues to be a sports club.

supermarket and no one is able to change that. Peter thus is not excluded from participating as a peer.¹⁰³ Therefore, the absence of participation as a peer in this case does not conflict with his recognition as an equal and thus Peter can be included without participating as a peer.

3.2.3. *Needs principle*

The third principle says that one is included in a group if the individual needs a person has are taken into account. With needs I mean the needs that are essential for a person's survival, flourishing and well being as a social creature. Most of the time people will be able to attend to these needs by themselves. But under certain circumstances they will need the care of others to attend to these needs. Attending to these needs is at the heart of Kittay's notion of connection-based equality.

If we think of each person as some mother's child, then we consider what is owed to a mother's child by virtue of its being vulnerable to the extent that the child is dependent upon the mother for its well-being. [...] The maternal paradigm is extended analogically to whatever situation we may be in where we *need* to be cared for – where our survival, our flourishing and our well-being as social creatures depend on the extension of another's care, concern, and connection to us.¹⁰⁴

With taking one's needs into account I mean that not only do others have to take care of you, when you are unable to do so yourself, but also that others pay attention to your needs. This is important, because if others do not concern your needs at all, they might thoughtlessly interfere with the fulfillment of your needs. Or it might be ignored that you have to be provided with means to take care of the fulfillment of your own needs. For example, if the need of someone in a wheelchair to go to the toilet is not taken into account by society then there probably will not be any disabled toilets in

¹⁰³ One can argue that he is excluded from participation as a peer by his disability. But as I see it, one is only excluded when there is a way in which human action could change the situation. In Billy's case nothing can be done to let him participate as a peer. Therefore, he is not excluded from participation as a peer, he is just unable to participate as a peer (regardless of the aids and support he receives from others).

¹⁰⁴ Eva Feder Kittay, *Love's Labor*, 70.

public buildings. It is common for societies to take the needs of people into account; for example in providing public toilets, a healthcare system, education, roads, laws restricting working hours or requiring silence after a certain time. But it is not evident that the basic needs of all people in society are taken into account. The difference in embodiment of people with disabilities may give rise to different needs or require different means for fulfilling common needs, think again of the disabled toilet.

As Rob Imrie points out it is important to recognize the differences in needs between people (with disabilities). “As previous research suggests, it is commonplace for disabled people to be defined as having walking difficulties or an impairment that confines them to a wheelchair [...]. These definitions are problematical because they fail to recognise the diversity of physical and mental impairments and the often conflicting and different mobility needs of different categories of (disabled) people.”¹⁰⁵ This observation also indicates that one should not try to take “the needs” of people with disabilities into account as they do not exist as such. Different people with different disabilities have different needs. The inclusion of people with disabilities is about the inclusion of different individuals with a disability and not about including people with disabilities as a group.

Being included means that one’s needs are taken into account even when they are different from the majority. It is perfectly possible that the mobility needs of someone in a wheelchair are fulfilled and thus have been taken into account, whereas those of someone with a visual impairment have not been taken into account. As Imrie points out, “although it is common for public buildings to provide ramps to facilitate wheelchair access, it is less so to see signage, texture, or colour coding of a type which provides ease of sight, direction, and communication to vision-impaired people and those with learning difficulties.”¹⁰⁶

An important question is: by whom should the needs of the individual be taken into account? Is that by all members of the group, or only by the ones making decisions? This is an important question because it tells us something about when the requirement of the *needs principle* is met, and thus when one is included. It is not a

¹⁰⁵ Rob Imrie, “Disability and Discourses of Mobility and Movement,” *Environment and Planning A* 32 (2000) 1644.

¹⁰⁶ *Ibid.*, 1645.

requirement of inclusion that one's needs are taken into account by every single individual member of a group in order to be able to speak of inclusion. But, on average every member should do so in order to speak of inclusion. Take again the example of physical access to the university. A professor entering the faculty building recognizes that other people are being part of the academic community that makes use of that building. Therefore, he takes their needs into account when he does not lock the door of the main entrance behind him when he enters the building in the morning. The other members do so equally when they do not park their bike in front of the entrance and thereby prevent other people from entering the building. When members of the academic community do not recognize that someone with a visual impairment may be part of their community and therefore do not take their needs into account, they may for example put their bags in the middle of the hallway when they go fetch some coffee, which could result in people with visual impairments stumbling over them. Now you can object that when someone with a visual impairment is left out of consideration, when someone leaves their bag in the middle of the hallway, that that does not result in the exclusion of people with visual impairments from the academic community. After stumbling, the visually impaired academic can get up and continue walking to the room she was heading at. I do agree that one is not excluded from a community when such a thing happens, even when it happens more than once.¹⁰⁷ But I do *not* think that one is therefore included. What I mean is that inclusion is something stronger than just the negation of exclusion. And this is what the three principles are meant to explain. The given examples show that fulfillment of the *needs principle* is something that concerns all members of the group.

The *needs principle* seems demanding, because how can all members of a community know what the needs of the other members are? Most of the time they do not even know each other by person. Therefore, I propose that they do not actually have to know the needs of all individual members in order to be responsive to them. As humans do all the time, they can make this requirement less demanding by using stereotypes. But even stereotyping can be done in a more inclusive way than may be common. One should not only take a white male in his forties as the one that has to

¹⁰⁷ On the condition that the one who leaves the bag there is just ignorant and does not do it with the intention to let a visually impaired person stumble.

be taken into consideration, when reasoning about the needs of the members of the academic community. One can think of Muslim women, gay men, someone in a wheelchair, someone with autism, someone with a hearing impairment, someone with Crohn's disease. But even trying to make an extensive list of the kinds of needs one should take into consideration concerning people with disabilities is more like a research project than something you can ask of person when he is determining where to put his bag. The amount of needs one can take into consideration during the daytime is limited. But not so limited, I would say, that there is no room for improvement. To ensure that also when one differs from the other members of a group in a way that is uncommon and that gives rise to very particular needs, one can be included, inclusion requires that the other group members are willing to take these specific needs into account when these are communicated to them.

What is meant by the *needs principle* is not that all needs have to be fulfilled, but that people's needs should not be ignored. I make this distinction, because there may be practical limits to the extent to which everyone's needs can be fulfilled. The practical impossibility to fulfill one's needs should not result in one being "un-includable." The fulfillment of everyone's needs as a requirement is too strong. But everyone's needs should be paid attention to, should be taken seriously and if possible should be fulfilled, this is what I mean with: should be taken into account. Most of the time taking needs into account does consist of fulfilling them. But, when it is impossible to do so, or when there are conflicting needs in a group, the *needs principle* prescribes that everyone's needs are paid attention to and are taken serious in making a decision as to how to meet everyone's needs as much as possible, although they cannot be fulfilled completely. If everyone's needs have been taken seriously into consideration in decision-making but the outcome could not result in the fulfillment of everyone's needs, one can still say that the requirement of the *needs principle* is satisfied. How inclusive decision-making can take shape will be further explained, under the heading of political inclusion, in the next chapter.

4. Social, Physical and Political Inclusion

In the previous chapter it has been explained how the *recognition of equality principle*, the *participation principle* and the *needs principle* can be united into one notion of inclusion. In this chapter it will be explained that one can distinguish three areas in which inclusion has to be realized in order to establish the inclusion of people with disabilities in society. There should be social, physical and political inclusion. This means that in each of these areas the three requirements of inclusion – namely, the *recognition of equality principle*, the *participation principle* and the *needs principle* – have to be fulfilled.

First of all, social inclusion will be discussed. Social inclusion consists of the social attitudes towards one, being such that they do not interfere with, or even support, the fulfillment of the three principles of inclusion. It will be explained that historically, people with disabilities have not been socially included. Realizing social inclusion of people with disabilities thus should be of concern for a society in order to become inclusive.

Second, physical inclusion will be discussed. Physical inclusion consists of the physical environment being accommodative to the differences between people, in such a way that it is compatible with the fulfillment of the principles of inclusion. It will be explained that the designed environment can affect the fulfillment of the three principles in various ways. The realization of physical inclusion thus plays an important part in the inclusion of people with disabilities in society.

Finally, political inclusion is about the organization of democratic decision-making and political debate. Political inclusion requires that all members of society are included in political debate in order to ensure that just decisions will be made. This entails the recognition of all members of society as equals who should be involved in decision-making. Besides, it has to be ensured that no one is excluded from participating as a peer in political debate, by allowing for different kinds of rhetoric. Political inclusion also has to do with how the concern for the needs of all members of society takes shape. It may not always be possible to fulfill everyone's

needs, and political inclusion enables a decision-making process in which difficult decisions about conflicting needs can come about.

4.1. Social inclusion

4.1.1. *The Recognition of Equality Principle and Social Inclusion*

People with disabilities [...] face considerable prejudice in many facets of daily life, as evidenced by many different commonplace experiences. Prejudice drives the still considerable sources of exclusion and helps determine the levels of access that a society allows individuals with disabilities. Prejudice plays a sizeable role in how people with disabilities are classified by society and in how persons with disabilities are represented in media. Prejudice also fuels the ways in which many members of society react to individuals with disabilities. Many people still regard persons with disabilities in terms of a range of stereotyping and oppressive perceptions, particularly feigned concern, sentimentality, indifference, or outright hostility [...]. The move toward social integration must be considered in light of the fact that integration for persons with disabilities still does not mean being considered an integral aspect of a society.¹⁰⁸

With this observation, Paul Jaeger and Cynthia Ann Bowman point at one of the core issues that hamper inclusion of people with disabilities in society, namely negative social attitudes towards people with disabilities. In order to be included in society one has to be socially included. This means, first of all, that one is recognized as an equal (the *recognition of equality principle*). In order to be recognized as an equal, one has to be regarded as more than “disabled.”

Jaeger and Bowman describe that someone’s disability long has been regarded as defining the characteristics of that person. “Regardless of the time period or the society, disability has tended to function as a “master status,” a classification that has

¹⁰⁸ Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability: Inclusion, Access, Diversity, and Civil Rights* (Westport: Praeger Publishers, 2005) 5.

more social import than anything else in defining an individual.”¹⁰⁹ Someone is a disabled employee, a disabled parent, a disabled student or a disabled musician.

If one is primarily conceived of as disabled, one is likely not recognized as an equal member of society, because with the classification of being disabled come certain beliefs, assumptions and stereotypes.¹¹⁰ According to Jaeger and Bowman: “[i]n general, individuals with disabilities have been socially classified as outsiders throughout history.”¹¹¹ Additionally, they explain that, “individuals with disabilities have been consistently classified as having little social value or as not part of society at all.”¹¹² Deborah Marks points out that “disabled people are frequently constituted as being isolated and dependent recipients of services rather than being productive and valued citizens.”¹¹³ Also, Anita Silvers recognizes the negative image that is attached to disability, “[r]egardless of their personal attainments, individuals identified with this class suffer from a paternalism similar to that which woman once endured. This presumption of incompetence is the burden of membership in what is viewed as a “weak” class incapable of the performances required for full social participation.”¹¹⁴ These negative images of people with disabilities testify of social attitudes towards people with disabilities that do not comply with the *recognition of equality principle*. In order for people with disabilities to be included in society, social attitudes should be in accordance with the recognition of people with disabilities as equal citizens.

In the past few decades progress is made, as the attitude towards people with disabilities is changing. Jaeger and Bowman consider how the change in accepted terms used to describe people with disabilities reflects a change in attitude towards those people. “The change has been away from equating the person with his or her impairment to describing the person as having an impairment.”¹¹⁵

Also, the adoption by the UN of the Convention on the Rights of Persons with Disabilities constitutes a change in the social attitude towards people with disabilities.

¹⁰⁹ Ibid., 12.

¹¹⁰ Ibid., 10.

¹¹¹ Ibid., 11.

¹¹² Ibid., 12.

¹¹³ Marks Deborah, “Disability and Cultural Citizenship: Exclusion, ‘Integretion’ and Resistance,” in *Culture and Citizenship* ed. Nick Stevenson 167 - 179 (London: SAGE publications Ltd., 2001). 171

¹¹⁴ Anita Silvers, “Formal Justice,” 54.

¹¹⁵ Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability*, 4.

According to Caroline Harnacke and Sigrid Graumann “it is widely agreed that the Convention constitutes a paradigm shift.”¹¹⁶ Persons with disabilities are, with the Convention, no longer seen as objects that receive society’s care. They are “first and foremost seen as persons, as subjects, who have rights like everyone else.”¹¹⁷

These changes indicate that social attitudes towards people with disabilities change as to be more inline with the recognition of people with disabilities as equal citizens. This may result in the fulfillment of the *recognition of equality principle* with regard to social inclusion.

4.1.2. *The Participation Principle and Social Inclusion*

Social inclusion is also about the fulfillment of the *participation principle*. Silvers gives a telling example of how the social conception of people with disabilities affects their opportunity to participate as peers:

Jenny Morris was a mother, a winning politician, an activist buoyed on the rising tide of a flourishing feminist movement. Others valued her presence and thought her life worth living, even envied her. But, at the age of thirty-three, Jenny Morris tumbled off a wall at the bottom of her garden and injured her lower spine so that she lost the ability to walk.

Morris retained all her political knowledge and skills, her relation with her child, her disposition to fight for social justice. Very little about her that had been of social value changed after the fall – certainly not the skills and knowledge she had demonstrated. Yet, hers was a social as well as a physical fall, for in the eyes of others, she found her life no longer seemed worth living in virtue of her disability.¹¹⁸

It is very difficult to participate as a peer when others do not conceive of you as someone who has skills and ambitions that are of equal value as that of others. The reluctance of other people to see one as more than disabled makes it impossible to

¹¹⁶ Caroline Harnacke and Sigrid Graumann, “Core Principles of the UN Convention on the Rights of Persons with Disabilities: An Overview,” in *Disability and Universal Human Rights: Legal, Ethical, and Conceptual Implications of the Convention on the Rights of People with Disability* edited by Joel Anderson and Jos Philips, 31–47 (Utrecht: SIM, 2012) 33.

¹¹⁷ Ibid.

¹¹⁸ Anita Silvers, “Formal Justice,” 37.

participate with them as peers, because in order to participate with them as a peer they need to let you participate with them as a peer.

As pointed out in the previous chapter, in order to be included one should not be excluded from participation as a peer. The social attitude of others may exclude one from participation as a peer, because others conceive of you as being less valuable and unfit to participate as a peer with them. In this way the *participation principle* plays a part in social inclusion. In order to be socially included the social attitude towards one should not exclude one from participating as a peer.

4.1.3. *The Needs Principle and Social Inclusion*

Finally also the *needs principle* plays a part in social inclusion. For example, the need of people with disabilities to have relationships and start a family has been ignored much because of the social conception of people with disabilities. Silvers quotes disability researchers Lamd and Layzell who state that:

There is an unspoken taboo about relationships and disabled people. Disabled people's sexual and emotional needs are rarely included in any ... representation in everyday life. ... This reinforces the public's attitudes and expectations toward disabled people as seeing them as "sick and sexless" rather than as participating in full sexual and family relationships.¹¹⁹

The need of people with disabilities to have (sexual) relationships has been ignored. The social attitude that people with disabilities are not up for having a relationship is likely to have hampered their opportunity to fulfill this need. How can you find a partner when potential partners do not take you seriously as someone you can start a relationship with? By reinforcing this attitude the universal need for having a sexual relationship, which exists among people with disabilities as well, is not taken into account by society. This means that the requirement of inclusion stating that one's needs should be taken into account is not met. Furthermore, one is excluded from participating in sexual relationships. This illustrates that the fulfillment of the *needs principle* can also be affected by social attitudes. Social inclusion also consists of

¹¹⁹ Ibid.

social attitudes being such as to comply with the *needs principle*, they should be in accordance with people's needs being taken into account.

One sees that for example in the Dutch society the social attitude with regard to people with disabilities having relationships is changing, as a sexologist is now part of the staff of some rehabilitation centers.¹²⁰ Also, in the media you see people with disabilities who do have relationships and start a family. Take for example the BBC documentary *We Won't Drop the Baby*¹²¹ in which the story of Laurence Clark and his wife Adele who both have cerebral palsy is told. Laurence and Adele are filmed in the documentary during the period in which they were having their second child. Or take the Channel 4 series, *The Undateables*, in which singles with a disability are followed in their attempts to find a relationship. In this series it is displayed that people with disabilities are persons who want to have a partner and who are just as "dateable" as anyone else.¹²²

To summarize, social inclusion means that social attitudes towards one do not conflict with the recognition of one as an equal. And that one is not restricted by social attitudes of others in participating as a peer or fulfilling one's needs. Positively, it means that one is recognized as an equal member of the community, that social attitudes are supportive of one's opportunity to participate as a peer and that social attitudes are responsive to one's needs. Nevertheless, social inclusion is not the only kind of inclusion that has to be established in order to realize the inclusion of people with disabilities in society. In the next section it will be discussed how also the physical environment plays an important part in the inclusion of people with disabilities in society.

¹²⁰ Maartens Kliniek, "De seksuoloog: geen luxe maar bittere noodzaak," interview with Paul Rabsztyn, <http://www.maartenskliniek.nl/nieuws/archief/revalidatie/1936961/>, visited on May 2014.

And Sophia Revalidatie, "Behandelteam: seksuoloog," <http://www.sophiarevalidatie.nl/revalideren/algemene-informatie/jongeren/behandelteam/seksuoloog>, visited on May 2014.

¹²¹ BBC, Zoe Callan, "We Won't Drop the Baby," Documentary produced and directed by Zoe Callan, broadcasted 4 April 2012, <http://www.bbc.co.uk/programmes/b01dwggn>, visited on May 2014 and http://www.youtube.com/watch?v=wSn3r0_VpsE, visited on May 2014.

¹²² Channel 4, first episode broadcasted 3 April 2012, "The Undateables." Real-life television show, <http://www.channel4.com/programmes/the-undateables>, visited on June 2014.

4.2. Physical Inclusion

In this section the physical space is analyzed in terms of inclusion. This means that it is explored how the design of the physical environment plays a role in the realization of the *recognition of equality principle*, the *participation principle* and the *needs principle*. It becomes clear that the physical environment plays a crucial part in the fulfillment of these principles and thus in the inclusion of people with disabilities in society. Physical inclusion consists of the physical environment being in compliance with the three principles of inclusion.

More than any other marginalized group, people with disabilities are affected by exclusionary design of physical space. Human beings are used to shaping the physical environment in order to better fit their needs and interests. Therefore, attention should be paid to the continuing existence of physical design that contributes to the exclusion of people with disabilities.

4.2.1. Recognition of Equality Principle as a Requirement for Physical Inclusion

Physical inclusion has everything to do with access. According to Jaeger and Bowman “access can best be understood as the right to participate equally in ways that are not constrained by physical or mental limitations.”¹²³ This starts with being able to be present at a particular site. The entrance of a building can display that the community using that building does not recognize certain people with disabilities as equals as particular people are denied access by the design of the entrance. As Jaeger and Bowman point out, “[a] tangible example is the preeminence of stairs, revealing social discounting of those who cannot walk.”¹²⁴ Jaeger and Bowman support the claim that access has to do with recognition of equality as they point out that only “when persons with disabilities are socially included and classified as having value, then issues of equal access become social concerns.”¹²⁵

The designed physical environment attest of either the recognition or the misrecognition of the equality of people with disabilities. The designed physical environment thus plays a role in whether the *recognition of equality principle* is met.

¹²³ Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability*, 63.

¹²⁴ *Ibid.*, 9.

¹²⁵ *Ibid.*, 63.

People can be physically included or excluded, meaning that the designed physical environment can either satisfy the requirements of inclusion or fail to satisfy them.

Although the physical environment plays a crucial role in the inclusion of people with disabilities, physical objects are not the things that are capable of recognizing anyone as an equal. They attest of whether the people who designed them and who use them recognize people with disabilities as equals. But, as is explained in the following discussion of Tanya Titchkosky's analysis, of how people relate to the inclusiveness of the physical environment, people do not always acknowledge that the designed physical environment displays their recognition or misrecognition of people with disabilities as equals.

Tanya Titchkosky indicates that how people relate to the build environment, that is inaccessible to people with disabilities, may teach us that disability is viewed as excludable.¹²⁶ She illustrates this with the case of the absence of a wheelchair accessible toilet at the University of Toronto.¹²⁷ She found that people at the university were giving reasons for the absence of an accessible toilet and thereby made it excusable that people with disabilities were excluded.¹²⁸ She states that “[u]nless the relation between environment and its participants is theorized and thereby disturbed, disability will continue to be included as an excludable type even as the physical environment changes.”¹²⁹ This points out how important it is for the inclusion of people with disabilities that they are recognized as equal members of society who may not be excluded. And that it is acknowledged that recognition of people with disabilities as equal members of society takes shape in the design of the build environment.

Titchkosky points at some obstacles on the way of translating recognition into an accessible environment: “[n]arratives of justification make it ordinary to disregard the absence of an accessible washroom as a noticeable barrier. The washroom is not missing; what is missing is any need to respond to such a barrier to participation.

¹²⁶ Tanya Titchkosky, “‘To Pee or Not to Pee?’ Ordinary Talk about Extraordinary Exclusions in a University Environment,” *Canadian Journal of Sociology* 33 (2008) 45.

¹²⁷ *Ibid.*, 42.

¹²⁸ *Ibid.*, 45.

¹²⁹ *Ibid.*, 46.

Justification, with its inherent lack of alarm, makes it reasonable not to notice the missing accessible washroom.”¹³⁰ People are not alarmed by the presence of an exclusionary practice such as the absence of an accessible washroom. Simultaneously, Titchkosky observes, people also consider it to be ordinary to say that they care for the disabled.¹³¹ This seems to lead to the contradictory situation in which accessibility for people with disabilities is considered to be important and at the same time society fails to provide proper access.

The absence of inclusive physical space, according to Titchkosky, has often been explained with phrases such as “things just weren’t built with people with disabilities in mind”¹³² indicating that people with disabilities were not recognized as equal members of society who are amongst the ones entitled to use a certain building. From Titchkosky analysis of the reactions of people with regard to the inaccessibility of certain buildings, and Brendan Gleeson’s discussion of access regulations, it can be learned that: the fact that we have inherited a range of inaccessible buildings is treated as an inconvenient truth, and a continuation of using these buildings is not interpreted as the continuation of an unjust exclusionary practice.¹³³

Furthermore, restoring past failures to provide access for people with disabilities requires recourses. “In many fights for access, “historical oversight” is a rhetorical device suggesting that nothing can be done because a building structured by old standards is too old and too expensive to change, while maintaining the ordinary sense that things would change were it not for this stifling history.”¹³⁴

But, also with the establishment of new physical environments accessibility may be discarded when it has to compete with financial interests, as Gleeson illustrates with the example of “the decision of public and private transport providers [in New Zealand] to purchase buses which disability groups considered inaccessible.”¹³⁵ Gleeson indicates that in response to a complaint about this decision the transport

¹³⁰ Ibid., 53.

¹³¹ Ibid., 54.

¹³² Ibid., 42.

¹³³ Tanya Titchkosky, “To Pee or Not to Pee?” and Brendan Gleeson, *Geographies of Disability* (London: Routledge, 1999), 181-194.

¹³⁴ Tanya Titchkosky, “To Pee or Not to Pee?” 54.

¹³⁵ Brendan Gleeson, *Geographies of Disability*, 191.

manager of a regional council answered that he “was concerned about cost being imposed on ratepayers.”¹³⁶

By shifting the focus of matters of accessibility away from inclusion and towards discussions about financial resources it is easily forgotten that accessibility is part of what the inclusion of people with disabilities in society consists of. Framing the discussion *solely* in terms of financial recourses testifies of misrecognition of people with disabilities as equal members. Whether or not people with disabilities are provided access has become a matter of resource allocation instead of recognition of their equality. The absence of access becomes reasonable instead of exclusionary.

This discussion illustrates that physical inclusion requires the recognition of people with disabilities as equals. And, furthermore, that people should be aware of the fact that the design of the physical environment plays a crucial role in the inclusion of people with disabilities, and that the environment is not something static but that it can be changed to become more inclusive. The design of the physical environment should first and foremost be evaluated in terms of inclusion, other factors such as resources only come in second.

4.2.2. Participation Principle with Regard to Physical Inclusion

A paradigm example of how the physical environment may interfere with someone’s ability to participate as a peer is that someone who uses a wheelchair is excluded from participation in a certain practice when that practice takes place in a room that can only be entered by walking the stairs. But, whether or not someone with a disability is able to participate as a peer is not only determined by having access. In order not to exclude people with disabilities from participating as peers by the design of the physical environment, attention should be paid to what participation further requires. For instance, Jaeger and Bowman point out “(a)ccessible routes into and within buildings often separate persons with disabilities from others in the structure or even completely hide persons with disabilities from view of other people.”¹³⁷ This makes it for example difficult for people who use a wheelchair to go to a theater together with a group of friends. In some theaters, people, using a

¹³⁶ Ibid.

¹³⁷ Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability*, 66.

wheelchair, need to enter the theater through the back door making use of small elevators. It thus becomes impossible to enter the theater together with a group of friends. Furthermore, when the wheelchair spots in the theater are situated at the first or second rank someone in a wheelchair is not able to join his friends who sit on the balcony. Physical inclusion demands that the design of the environment is such that people with disabilities are able to join people without disabilities in physical space, otherwise they will not be able to participate as peers.¹³⁸

The example of the theater illustrates moreover that whether the physical environment allows for participation as a peer is distinct from whether one's needs are taken into account. One can say that the needs of someone using a wheelchair have been taken into account, as attention has been paid as to what a person using a wheelchair needs in order to enter the theater and to watch the performance. The separation of the wheelchair user from people who are able to walk, by the design of the physical environment, excluded the person in a wheelchair from participating as a peer with the other members of the audience.

However, physical inclusion is not only about the design of buildings. It is also about the design of other things we use in daily practices. People with disabilities can be excluded from participating as peers by the way information is provided. For example, when information is only provided by voice output people with hearing impairments are unable to perceive it. This can hamper their ability to participate as peers in society when traffic information at railway stations is only provided by a voiceover.

When information is only provided in text, and for instance not in braille, people with visual impairments are excluded. Think of the liturgy booklet in church, when this is not provided in an accessible format for people with visual impairments they cannot participate as peers in the service.

As Jaeger and Bowman explain, people with cognitive or learning impairments may be excluded as well by the way in which information is made accessible.

¹³⁸ Furthermore people with disabilities should also be able to join each other. Some places do provide for example wheelchair access, but only to one wheelchair at the time.

For individuals with learning disabilities, intellectual access is a keenly important issue, as their ability to understand certain content may hinge on how it is organized and represented. For example, if information on a Web site is poorly organized and cluttered, the content of the site will be intellectually inaccessible to people with certain learning disabilities. Clarity in organization and representation is similarly essential for intellectual access for individuals with cognitive disabilities.¹³⁹

Lacking access to relevant information may exclude one because in the information age it limits one's opportunities to proceed in basic activities, and thus to participate as a peer in society. Being able to use the internet is required for participating in a lot of activities. For example, if one is unable to use Facebook because the information is cluttered, one may miss out on social events in one's social network announced on Facebook.

People with cognitive disabilities' need for information is not taken into account when information is only available in for them inaccessible formats. Taking care of one's own health requires that one has access to information about insurances, doctors, medicines and more. Physical inclusion does encompass access to information. An inclusive society should ensure that people with disabilities have access to the information they need to fulfill their needs and to be able to participate as a peer.

Most of the time, a failure to take people's needs into account in designing the physical environment excludes people with disabilities from participating as peers, as well. In the next section it will be explained how the needs principle plays a role in the realization of physical inclusion.

4.2.3. *Needs Principle*

Physical inclusion cannot be realized without the *needs principle* being fulfilled. This means for example that in the case of someone using a wheelchair there has to

¹³⁹ Paul T. Jaeger and Cynthia Ann Bowman, *Understanding Disability*, 66.

be a disabled toilet. Or in the case of someone with dyslexia that exams are provided in an accessible format.

It is not always the case that the special needs of someone with a disability have to be taken consciously into account, in order for a design to be accommodative. Take for example the operating system MS DOS, as Silvers describes, this operating system (without being designed for that purpose) allowed visually impaired people to use the computer, because it was easily compatible with software that reads out loud what is displayed on the screen. The next operating system Windows made use of a graphic user interface that made use of pictograms. Without access to the source code, the software visually impaired people used to convert what was displayed on the screen to voice output could not be made compatible with this new operating system.¹⁴⁰ DOS was accessible for visually impaired people because (even without access to the source code) software was developed that translated what was displayed on the screen, into voice output. Because Windows had a different interface it was no longer possible to develop such software without access to the source code. This example tells us, that something may unknowingly be made accessible for people with disabilities. But it also points at the importance of the *needs principle*, because when operating systems are designed in compliance with the *needs principle*, the needs of people with disabilities are taken into account. And thus, a new operating system will not be designed in such a way, that some people are suddenly unable to use it. With the prevalence of DOS, visually impaired people were having jobs that required working on the computer. With the rise of Windows, they could no longer participate as an employee, because this required using Windows.¹⁴¹ The needs of people with visual impairments were not been taken into account, and that resulted in them being physically excluded from they jobs. Because, they simply were no longer able work with the computer at their work place. This example stresses the importance of needs being taken into account, because failure to do so easily results in exclusion.

But the DOS/Windows example also shows us how physical inclusion plays a role in social inclusion, as the presence of visually impaired people in the workforce

¹⁴⁰ Anita Silvers, "Formal Justice," 107.

¹⁴¹ Ibid.

shows to other people that being disabled does not mean that one is unfit to work. In this way physical inclusion is crucial for the promotion of social inclusion.

It is important to understand that physical inclusion of people with disabilities in society is very comprehensive. It encompasses both the public sphere and the private sphere. Think of transportation means, work places, schools and universities, medical facilities, shops, commercial institutions, places where one can have leisure time, sport facilities but also private homes. And people with disabilities do not only have to be able to enter all these facilities, but the designed environment should also equally facilitate their participation as a peer.

Creating an environment that is equally accessible for all seems to be not always possible. As Tom Shakespeare points out:

[W]heelchair users demand level access. Yet people with mobility issues who do not use wheelchairs may find that steps are safer and easier for them than ramps. Blind people may find that kerb cuts that liberate wheelchair users make it difficult for them to differentiate pavement from road, and leave them vulnerable to walking into the path of a vehicle. Wheelchair users may have problems with tactile paving that gives locational cues to visually impaired people.¹⁴²

On the one hand, we face the problem of people with disabilities being physically excluded, on the other hand, it seems impossible to make the environment accommodative to everyone. It is important to note, that the impossibility to provide equally accessible environments for everyone does not mean, that one does not have to try to make the environment more universally accommodative.

Priority setting with regard to physical inclusion brings us to the third mode of inclusion, namely political inclusion. Political inclusion should make it possible to make fair decisions with regard to how to decide between different ways to accommodate the environment to the abilities of different people.

¹⁴² Tom Shakespeare, *Disability Rights and Wrongs Revisited* (Abingdon: Routledge, 2014) 37.

4.3. Political inclusion

The above example of a dilemma one may face when striving for physical inclusion illustrates that it is very important to have means to make good decisions in non-ideal situations. Political inclusion should be realized in order for society to generate good decisions. Iris Marion Young gives an extensive account of the inclusion of minority groups in democratic practices in her book *Inclusion and Democracy*.¹⁴³ Young conceives of democracy as being connected to justice. According to her there is “a tight theoretical connection between democracy and justice; under ideal conditions of inclusive political equality and public reasonableness, democratic processes serve as the means of discovering and validating the most just policies.”¹⁴⁴ Therefore, political inclusion should be promoted.

Another reason why political inclusion should be promoted, is that being a citizen of a democratic country involves having the opportunity to participate in politics. People with disabilities should not be excluded from politics, as this comes down to excluding them from participating as peers in society. The three principles of inclusion – the *recognition of equality principle*, the *participation principle* and the *needs principle* – also play a part in the realization of political inclusion.

First, it is argued that political inclusion promotes justice in the outcome of the political decision-making process. Then, it is explained how political inclusion can take shape by the realization of the three principles of inclusion in the organization of political debate. Finally, it is explored how political inclusion also plays an important role in how society fulfills the *needs principle*.

4.3.1. Democracy and Inclusion

Young is an advocate of a deliberative model of democracy. She favors this model because, compared to for example an aggregative model of democracy, according to her, “[i]t is the best way to think about democracy from the point of view of an interest in a politics of inclusion and promoting greater justice.”¹⁴⁵

¹⁴³ Iris Marion Young, *Inclusion and Democracy* (Oxford: Oxford University Press, 2000).

¹⁴⁴ *Ibid.*, 17.

¹⁴⁵ *Ibid.*, 26.

In the deliberative model democracy is a form of practical reason. Participants in the democratic process offer proposals for how best to solve problems or meet legitimate needs, and so on, and they present arguments through which they aim to persuade others to accept their proposals. Democratic process is primarily a discussion of problems, conflicts, and claims of need or interest. Through dialogue others test and challenge these proposals and arguments. Because they have not stood up to dialogic examination, the deliberating public rejects or refines some proposals. Participants arrive at a decision not by determining what preferences have greatest numerical support, but by determining which proposals the collective agrees are supported by the best reasons.¹⁴⁶

Inclusion is one of the normative ideals entailed in this model of democracy. According to Young, “a democratic decision is normatively legitimate only if all those affected by it are included in the process of discussion and decision-making.”¹⁴⁷ As she conceives of inclusion, it is an ideal that “embodies a norm of moral respect.”¹⁴⁸ Because persons are treated as mere means if they are expected to abide by rules determined without their voice or interest being taken into account. In other words, in order *not* to treat the persons affected by a decision as means they should be included in the decision-making process. But for Young, inclusion does not only consist of being included in decision-making, it also means being *equally* included in the democratic process. This means that all “ought to have an equal right and effective opportunity to express their interests and concerns. All also ought to have equal effective opportunity to question one another, and to respond to and criticize one another’s proposals and arguments.”¹⁴⁹ As such the *recognition of equality principle* is part of political inclusion.

4.3.2. *Internal and External Inclusion*

Young points out several ways in which people can be excluded from democratic decision-making. First of all, she distinguishes between external and internal

¹⁴⁶ Ibid., 22-23.

¹⁴⁷ Ibid., 23.

¹⁴⁸ Ibid.

¹⁴⁹ Ibid.

exclusion. External exclusion means that those who are affected by a certain decision, are left out of the fora of discussion and decision-making. Internal exclusion refers to situations in which persons are present at the discussion or decision-making fora, but at the same time their concerns are not taken equally into account. Because they are, for instance, not recognized by others as partners in the discussion, or their way of expressing themselves is not considered to be appropriate, or their perspective and background presuppositions differ significantly from the majority and therefore their concerns are not understood properly.¹⁵⁰

External exclusion mainly consists of matters that have to do with physical inclusion. If for example the sites of political fora are not accessible, or people lack the means for transportation, people may be excluded from political participation. But also the way in which discussion is organized needs to be accessible for everyone. For example people with hearing impairments may need a sign interpreter. Besides, the program and invitations for events should be provided in a format accessible for people with visual impairments. Realizing external inclusion much coincides with physical inclusion.

Internal exclusion has to do with how the discussion takes shape. Young describes three modes of political communication – greeting, or public acknowledgement, affirmative uses of rhetorics and narrative – that are instructive for understanding internal political inclusion. The *recognition of equality principle*, the *participation principle* and the *needs principle* do figure in the discussion of these three modes of communication that illustrate how internal inclusion can be realized.

4.3.2.1. Greeting

The first mode of communication Young discusses is greeting. According to Young, this is the moment of communication in which a speaker “announces her presence as ready to listen and take responsibility for her relationship to her interlocutors, at the same time that it announces her distance from the others, their

¹⁵⁰ Ibid., 52-53.

irreducible particularity.”¹⁵¹ By greeting, one acknowledges the other as a participant in communication and acknowledges the other’s distinctiveness. This can be seen as making one’s recognition of the other explicit. Greeting thus is part of complying with the *recognition of equality principle*. According to Young, this is important in political communication because “democratic legitimacy requires that all those affected by decisions should be included in discussions that reach them.”¹⁵² The moment of greeting constitutes the starting point of such discussion.

Greeting names those communicative political gestures through which participants in democratic discussion recognize other specific groups as included in the discussion that will issue in decisions. By such gestures of greeting, discussion participants acknowledge that they are together with those they name, and that they are obliged to listen to their opinions and take them seriously.¹⁵³

By greeting one makes explicit that one intends to include the other in the political discussion and decision-making process. Thus, as a sign of recognition of the other as an equal, greeting is part of inclusive political discussion.

4.3.2.2. *Rhetoric*

The second mode of communication important for internal inclusion in political communication, Young explains, is rhetoric. By excluding particular forms of rhetoric certain people may be excluded from participating as peers in political debate. Amongst rhetoric Young understands: the emotional tone of the discourse, the use of figures of speech, forms of communication that do not involve speech (“such as visual media, signs and banners, street demonstration, guerrilla theatre, and the use of symbols in all these contexts”) and the way in which one adapts one’s communication to a particular audience and their particular assumptions, history and idiom.¹⁵⁴ Young emphasizes rhetoric as a mode of political communication in order to point out that

¹⁵¹ Ibid., 59.

¹⁵² Ibid., 61.

¹⁵³ Ibid.

¹⁵⁴ Ibid., 65.

“any discursive content and argument is embodied in situated style and rhetoric.”¹⁵⁵ As she explains, for example, some modes of emotional speech are not taken seriously in political debate, because of the presumption that political speech should be rational and free of emotion.¹⁵⁶ People who are not able (or used) to express themselves in the conventional neutral way are then excluded from political debate. By pointing out that this way of expressing does not have a special feature that makes it more suitable for political debate, it can be understood that one should acknowledge other ways of expression in political debate as not to exclude these people from participating as peers. Political inclusion thus requires the fulfillment of the *participation principle*.

In the case of disability, people with a hearing impairment may want to express themselves with sign language. People with cognitive impairments may also make use of different rhetoric to express themselves. Political debate being open for different forms of rhetoric ensures that people are not unnecessary excluded from participation as peers in politics. It even opens up the possibility to include people who are not able to express themselves at a political fora. Using different rhetoric, e.g. making use of a medium such as video, people who are unable to express themselves in political debate such as people with severe cognitive disabilities can be included. By showing a documentary about the life of someone with a severe cognitive impairment, her experiences and needs can become part of political deliberation. This is one way in which people unable to participate in political debate in the conventional way, can still be included in a different manner. The medium of video documentaries can also play a role in the third mode of communication Young describes. This shows how being accommodative to different rhetoric ensures that people are not excluded from participating as peers in political debate.

4.3.2.3 Narrative

The third mode of communication Young describes as important for inclusive political debate, is narrative.¹⁵⁷ This may prove helpful when the background assumptions and experiences of the different parties in communication are so different that they have trouble understanding each other. By telling narratives people can

¹⁵⁵ Ibid., 64.

¹⁵⁶ Ibid., 63-64.

¹⁵⁷ Ibid., 70-71.

make an argument better understandable from the point of view of the audience. For able-bodied people it is difficult to understand the experience of having a disability. By telling about their experience with having a disability, people with disabilities can make accessible to able-bodied people what kind of problems they face and what kind of misunderstandings are prevalent about having a disability. This is very important for the inclusion of people with disabilities in political debate because many political decisions particularly affect the lives of people with disabilities. Again, for example documentaries but also books can prove useful to communicate a narrative in support of a particular argument or decision. But just taking the time to listen to spoken narratives may prove important as well. Narratives play an important role in communicating needs and this is important for being able to fulfilling the *needs principle* of inclusion.

4.3.3. *The Needs Principle*

Political inclusion plays an important role in how society gets to know the needs of the different people in society. This is particularly important as society has to fulfill the *needs principle* and thus take everyone's needs into account. As mentioned before, it is not easy to acquire knowledge of how one can be responsive to the needs of one's fellow citizens. By realizing political inclusion one establishes that the knowledge of society about itself and the needs of its members improves. As Young puts it:

Some partialities and misunderstandings can best be exposed by discussion with differently situated others. Susan Wendell offers one example of how the experience and perspective of a structural social group can contribute to the social knowledge of everyone in order to promote more justice. When people with disabilities have the opportunity to express their perceptions of biases in the socially constructed environment or expectations of functions needed to perform tasks, then everyone learns how to see the social environment differently.¹⁵⁸

¹⁵⁸ Ibid., 117.

Political inclusion thus enhances the knowledge about the different perspectives people have on practices in society. Thereby it becomes possible to take the needs of the people in society into account.

But then the question rises as to how society deals with those needs. In political deliberation the needs of different people or groups in society are taken into consideration and together with all parties involved a good solution for the situation at hand should be found. This can entail that not all needs can be fulfilled at the same time. Some people or groups may have conflicting needs, and resources are always scarce, thus choices have to be made. Having political inclusion ensures that all the parties involved in a particular decision are able to express their concerns and take part in making a decision. Hereby, decisions are not (only) made in the interest of the most powerful or the majority. Inclusion means that all people involved give concern to the needs of others and deliberate about the best way to meet these different needs.

When the people affected by a decision are not included in the political debate (or their needs have not been taken into consideration) and the outcome does harm their needs, this outcome can be considered unjust. But, if this decision has been made in an inclusive way, it can be a just one. This will be explained in what follows.

According to Linda Barclay, justice cannot demand something that one cannot reasonably expect society to provide.¹⁵⁹ Although a lot of the disadvantages people with disabilities face are socially constructed that does not mean that justice demands that all these disadvantages should be taken away by altering the social component. Barclay states that “[i]f the social contribution to disadvantage is unavoidable, or only overcome at unacceptable cost, including opportunity cost, then it is incorrect to assume that it is a source of injustice.”¹⁶⁰ This means that the existence of some disadvantages for people with disabilities, even when they are socially constructed, may be unavoidable even in a just society.

Justice does not have to be only about socially constructed disadvantages, the not socially constructed disadvantages may even prove more difficult to mitigate. As has been explained in the first chapter, for some people to be able to participate as an equal member of society requires certain aids and support such as wheelchairs, sign

¹⁵⁹ Linda Barclay, “Justice and Disability: What Kind of Theorizing Is Needed?” *Journal of Social Philosophy* 42 (2011), 281.

¹⁶⁰ *Ibid.*, 281.

language interpreters or extra training to acquire skills such as reading or walking. An inclusive society has to ensure that people are not excluded from participation because they lack the resources necessary for acquiring aids and support that will provide them the capabilities essential for participating as peers. But it is difficult in practice to give content to such a requirement. Does it mean that all paraplegic have to be provided a robotic exoskeleton in order to be able to play football? Or is a wheelchair that enables one to move around by oneself sufficient? The resources available in society do play an important role in determining what aids and support can be provided. Moreover, it has to be decided what capabilities are essential for participating as a peer. Walking may not be essential for participation, as moving around independently may be. This may raise the question whether to spend resources on curing an injury that deprives one of the ability to walk or on providing a wheelchair in order to restore the capability to move around independently. Although walking may not prove to be essential for participation, the individuals needs have to be taken into account as well. Taking this into account may prove restoring one's ability to walk to be more important. For example because walking can have a positive effect on one's health where sitting all day may cause osteoporosis.^{161,162} This illustrates how following the requirements of inclusion in decision-making is not only about the establishment of capabilities, but that it is also about needs of the individual, for instance with regard to health. However, some authors, such as Martha Nussbaum, define health also as a capability.¹⁶³ It exceeds the scope of this thesis to explore the different conceptions of health in order to determine whether health concerns are better placed under the heading of capabilities necessary for participation or needs of the individual. Either way health is of concern for inclusion.

How to deal with claims for justice is a political matter. Political inclusion is a way to ensure that the political decision-making process is just. Only when a decision came about in an inclusive process one can be sure that the decision is a just one. Even when the outcome is not optimal for everyone. Realizing political inclusion thus

¹⁶¹ I.M. Lee and D.M. Buchner, "The Importance of Walking to Public Health," *Medicine and Science in Sports and Exercise* 40 (2008) 512–8.

¹⁶² B.J. Kiratli, "Immobilization Osteoporosis," In *Atlas of Osteoporosis*, 149-164 (Philadelphia: Current Medicine Group, 2003).

¹⁶³ Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge: Belknap Press, 2007) 76.

provides a legitimate way to make difficult decisions about for example access for people with disabilities in a situation where no optimal outcome is possible.

It does not only tell us that able-bodied people should be responsive to the needs of people with disabilities but also that people with disabilities should be responsive to the needs of people with different disabilities and of people without disabilities. In this way, people with disabilities are equally required to take responsibility for the decision at hand, and that gives them the opportunity not only to demand what is best for them, but also to deliberate about how this can be reconciled with the needs and interests of others and the limited amount of resources at hand.

4.4. Conclusion

In this chapter it has been argued that in order to realize an inclusive society, social, physical and political inclusion have to be established. In these three areas the three principles that form the requirements of inclusion – the *recognition of equality principle*, the *participation principle* and the *needs principle* – have to be met. It has been explained how society may fail to include people with disabilities socially, physically and politically.

Social inclusion is about the social attitude people have towards one. These attitudes may attest of one not being recognized as an equal member of society. Moreover, negative social attitudes towards people with disabilities can lead to their exclusion from participating as peers. Furthermore, social attitudes can attest of one's needs not being taken into account or even interfere with the fulfillment of one's needs. The realization of social inclusion thus forms an important aspect of the completion of an inclusive society. In order to be included in society one has to be socially included in society.

Physical inclusion incorporates the way in which the physical environment affects the fulfillment of the three requirements of inclusion. The physical environment can attest of people with disabilities not being recognized as equal members of society. In that they are for instance not provided access. The physical environment can also exclude people with disabilities from participation as a peer. Finally, in the design of the physical environment the needs of people with disabilities should be taken into

account. When people with disabilities are not physically included in society then one cannot say that a society is inclusive to all.

Political inclusion is about the organization of democratic decision-making and political debate. All members of society should be included in political debate in order to ensure that just decisions will be made. This entails the recognition of all members of society as equals who should be involved in decision-making. Furthermore, it has to be ensured that no one is excluded from participating as a peer in political debate, by allowing for different kinds of rhetoric. Also, everyone's needs have to be taken into account, this requires that everyone should have to opportunity to communicate needs. This can be ensured for instance by acknowledging narrative as a mode of communication in political debate. But, political inclusion also has to do with how the concern for the needs of all members of society takes shape. It may not always be possible to fulfill everyone's needs. Political inclusion enables a decision-making process in which difficult decisions about conflicting needs can come about.

Social, physical and political inclusion for everyone has to be realized in order to establish the inclusion of all members of society. But as will be explained in the following chapters this does not take away all difficulties people with disabilities might experience. Still, the three principles of inclusion can provide guidelines as to how to deal with disability related difficulties in an inclusive manner.

5. Disability and Inclusion

In this chapter it is discussed how inclusion and disability relate to each other. It is argued that not all difficulties associated with disability disappear when social, physical and political inclusion are realized. In the following chapter, with the help of a case study, it is shown that the requirements of inclusion can also function as a standard against which policy can be tested. Even when physical, social and political inclusion are realized this is important for the inclusion of people with disabilities in society, because, as is explained in this chapter, even in an inclusive society disability may pose difficulties for the individual.

With the social model of disability as formulated in 1976 by the Union of the Physically Impaired Against Segregation (UPIAS), disability is interpreted as “the disadvantage of restriction of activity by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”¹⁶⁴ Impairment in this context refers to “[l]acking part or all of a limb, or having a defective limb or mechanism of the body.”¹⁶⁵

According to this understanding of disability, people with disabilities are people with physical impairments who experience the disadvantage of restriction of activity caused by social organization which does not take them into account. People with disabilities are thus excluded from participation in the mainstream of social activities. Inclusion encompasses that people with impairments (to speak in terms of the social model) are recognized as equal members of society and are not excluded from participation. In an inclusive society, disability, interpreted in accordance with the social model, would not exist. There would only be people with impairments. The distinction between disability and impairment enables one to distinguish between disadvantages that are constituted by the designed physical environment or by how society treats people with impairments and disadvantages that originate in the

¹⁶⁴ Colin Barnes, “Disability Activism and the Struggle for Change: Disability, Policy and Politics in the UK” *Education, Citizenship and Social Justice* 2007 2, 205.

¹⁶⁵ *Ibid.*

physical, mental or sensory deviation of people with impairments.¹⁶⁶ Therefore this distinction could be useful for an account of inclusion as developed in this thesis, as it enables one to identify instances of “biological dysfunction and [...] processes of social exclusion.”¹⁶⁷

Nevertheless, I have decided not to follow the social model in making this distinction. First of all because inclusion goes beyond disability (as socially constructed disadvantages). Inclusion concerns impairment as well. The *needs principle* illustrates this most clearly, as taking needs into account means taking impairments into account as they give rise to special needs an individual might have.

Shakespeare argues that one should not discount the impact of impairment on the lives of people with disabilities.¹⁶⁸ If inclusion would only be concerned with socially constructed disability then it would not include the impact of impairment that is not socially constructed. Silvers is an advocate of the social model of disability and as is explained in the first chapter she does not include the not socially constructed effects of disability as she only argues for the establishment of a level playing field. As is stressed in the first chapter with the help of Kittay’s notion of connection-based equality, in order to have a theory that includes all people equally, one should take people’s needs and dependency into account, even when they are not socially constructed.

Distinguishing between disability and impairment in the context of inclusion may give rise to the suggestion that only socially constructed disability and not impairment should be of concern for inclusion. But that is not the point of inclusion; inclusion of people with disabilities in society equally requires attending to socially constructed

¹⁶⁶ It is controversial to speak of disability or impairment in terms of disadvantage. I do agree with the many authors and disability rights activists that try to undo disability of the negative connotation as a burdensome condition. Nonetheless, I think that as soon as one has a proper understanding of what having a disability or impairment does and does not consist of, as many authors in the subject and people having an impairment do have, one may admit that there can be some disadvantages attached to impairments. For example not being able to dress oneself because of a physical impairment is not only disadvantageous because in western society it is socially expected that people get dressed before they leave their home and noncompliance to this norm would result in social disapproval. But it is also disadvantageous because getting dressed is essential to protecting one’s body against the weather. This constitutes a disadvantage.

¹⁶⁷ Bill Hughes and Kevin Paterson, “The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment,” *Disability & Society* 12 (1997) 328.

¹⁶⁸ Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 26-28.

disabilities as well as impairments. Both may require attention when fulfilling the three principles of inclusion. Therefore I use the term disability to refer both to socially constructed disability and impairment.

My use of the term disability is compatible with the critical realist approach of Shakespeare.¹⁶⁹ Shakespeare describes his position as follows:

The approach to disability that I propose to adopt suggests that disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability as a deficit or a structural disadvantage or alternatively a product of cultural discourse, a holistic understanding is required. Put simply, the experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. I accept that contextual factors will influence these intrinsic factors: impairment may be caused by poverty or war; personality may be influenced by upbringing and culture, etc. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society.¹⁷⁰

As inclusion is not a remedy for the not-socially-constructed aspects of disability, it is important to consider how to conceive of instances of disability that exist within the framework of inclusion. The societal changes in terms of social and physical inclusion, proposed in the previous chapter, basically address the changes advocates of the social model of disability primarily strive for. What is missing is how society should address particular problems people with disabilities have even when physical, social and political inclusion are established.

These problems will be included in the (inclusive) political decision-making process. Nevertheless, it is useful to consider a case that remains complicated even in an inclusive society, because this will show us that the principles of inclusion are

¹⁶⁹ Ibid., 72-91.

¹⁷⁰ Ibid., 74-75.

helpful in solving disability related issues that even an inclusive society faces. In the following chapter it will be discussed how long-term care can be provided in an inclusive manner.

6. A Case Study: Organizing Care in an Inclusive Way

Central to this chapter is the organization of long-term care some people with disabilities need. It is explored which guidelines for the organization of care can be abstracted from the three principles of inclusion for providing care in an inclusive manner.

First, it is discussed how a caring relation can take shape that testifies of the recognition of both the caretaker and the care receiver as equals. It is argued that a caring relation in which the caretaker and care receiver are allies in the fulfillment of the need for care of the disabled fits with the recognition of both the caretaker and the care receiver as equals. Also, in order to prevent both the caretaker and care receiver from getting trapped in a suppressive care-relation it should be possible for both to end the care relation without the dependent being left without any options for getting her need for care fulfilled. It is argued that the *participation principle* demands that the organization of care should not exclude one from participating as a peer in society. This requires that care is organized in a sufficiently flexible way with regard to time and place.

I take it for granted that the organization of care should be in accordance with the needs principle, as attending to needs is what care is about. Therefore the *needs principle* will not be extensively discussed in this chapter.

With the help of the abstracted guidelines, it is evaluated whether the personal assistance model of care based on direct payment lives up to these guidelines. It follows that the personal assistance model does meet most of the requirements of an inclusive way of organizing care but that it has some disadvantages as well.

6.1. Care and Inclusion

Some people with disabilities require care, as Mary B. Mahowald explains, the frequency and kind of care may differ significantly. “Some persons with disabilities, for example, require personal assistants around the clock; others require assistance on

a regular but not persistent basis; others require caregiving only occasionally, just as those who are currently able require it.”¹⁷¹

Caring tasks may range from cleaning someone, tying shoelaces, trimming nails or putting on lipstick to using and monitoring medical devices and equipment, requiring medical skills.¹⁷²

Care has to do with attending to the needs of another. The link between the *needs principle* of inclusion and care is easily made. One’s needs being taken into account sometimes comes down to being cared for. But inclusion requires not only that one’s needs are taken into account. It also requires the fulfillment of the *recognition of equality principle* and the *participation principle*.

6.1.1. *Is the Care-Relation Compatible with the Recognition of Equality Principle?*

In order for the care-relation to be compatible with the inclusion of both the care receiver and the caretaker in society the care-relation should be compatible with the *recognition of equality principle*. Thus, both the care receiver and the caretaker should be recognized as equals.

Silvers considers the caring relationship to be problematic for the recognition of the care receiver as an equal. Because, as she points out, “in a system in which caring for is the primary way able-bodied relate to disabled, it becomes socially incumbent upon the latter to profess incompetence even where they are more competent than the former.”¹⁷³ Although this is a serious point of concern, it is not inherent to a caring relationship that the care receiver is expected to profess incompetence. As Eva Feder Kittay, Bruce Jennings and Angela A. Wasunna point out “[a] person who cares for another with the attention required of good caring, provides care and assistance when it is needed and not when it interferes with the other’s justifiable need and desire to be exercising her own agency.”¹⁷⁴

¹⁷¹ Mary B. Mahowald, “A Feminist Standpoint,” in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, 209 - 251 (Lanham/Oxford: Rowman & Littlefield Publishers, 1998) 244.

¹⁷² Ibid.

¹⁷³ Anita Silvers, “Formal Justice,” 99.

¹⁷⁴ Eva Feder Kittay, Bruce Jennings and Angela A. Wasunna, “Dependency, Difference and the Global Ethic of Longterm Care,” *The Journal of Political Philosophy* 13 (2005) 458.

This being said, according to Silvers, there is another reason why the caring relationship is repressive with regard to the one being cared for. She believes that “the very structure of helping or caring relationships invites the marginalization of whoever is consigned to the position of dependence.”¹⁷⁵ Silvers explains this as follows:

Help-givers choose how they are willing to help, but help-takers cannot choose how they will be helped, for in choosing to reject proffered help one withdraws oneself from being helped as well as from being in a helping relationship. To relate to others primarily by being helped by them, then, implies subordinating one's choices to one's caretakers, at least in so far as one remains in the state of being helped.¹⁷⁶

Silvers describes the caring-relation or helping-relation as extremely one sided. In her view, it only consists of the caregiver providing the care receiver with a service. But, even though one person is providing care while the other is receiving it, there is place for mutual recognition in the care-relation. The one providing-care can recognize the other as an equal who has a voice in the providence of care. Recognizing the dependent as an equal means that one takes requests of the other serious. This does not mean that the caregiver should obey the care receiver unconditionally, because the caretaker has to be recognized as an equal person as well.

The care receiver is not the only one that may not be recognized as an equal in the care-relation. As Kittay e.a. point out, the caring-relation can also be repressive for the caregiver.¹⁷⁷ They explain that, for instance, the demand for “independent living” made by disability rights movements in the early 1970’s, as it seemed, could only be realized by caregivers who acted as if they were invisible.¹⁷⁸ It was comprehended that a severely disabled person can maintain independence when the care-giver functions as an instrument of her will.¹⁷⁹ “The disabled person needs the

¹⁷⁵ Anita Silvers, “Reconciling Equality to Difference,” 40.

¹⁷⁶ *Ibid.*, 40–41.

¹⁷⁷ Eva Feder Kittay, Bruce Jennings and Angela A. Wasunna, “Dependency, Difference and the Global Ethic of Longterm Care,” 466–467.

¹⁷⁸ *Ibid.*, 465–466.

¹⁷⁹ *Ibid.*, 466.

assistant to be invisible in order to maintain a sense of his independence, and sees the relationship as best achieved when entirely professional.”¹⁸⁰ According to Kittay, being invisible or transparent is part of good caregiving. The caregiver “must not interject her own desires, aspirations or wishes and so distort or fail to perceive the need she is there to meet.”¹⁸¹ But this invisibility comes at a price for the caregiver because she is likely not to be recognized as a person and valued accordingly when she is “invisible”.¹⁸²

The above pictured dilemma, between the need of the disabled for having control over the care she receives in order to be independent, and the interests of the caregiver who should be recognized as a person in her own right, has to be solved in order to be able to establish a care system that lives up to the *recognition of equality principle*. According to Kittay, a solution for this dilemma has to be found in a transvaluation of dependency. She proposes that “if we acknowledge our own dependency and vulnerability instead of demanding an illusory independence, one that can only be maintained by denying our connection to and reliance on others, then we do not need to make the caregiver invisible.”¹⁸³ However, the caregiver still has to be transparent to the needs of the care receiver. For Kittay being transparent differs from being invisible in that when one is transparent one can still be recognized as an equal person.

According to Kittay, the notion of independent agency is deeply rooted in our conceptions of justice and we need to rethink justice in such a way that dependency needs are no longer something negative. She suggests that “we want social structures predicated on a notion of justice which allows the extent and severity of our dependency needs to be rendered *indifferent* to our capacity to flourish. That is to say, whether or not we have dependency needs ought not be a critical determinant of whether or not we can lead flourishing lives. The burden of need should be neutralized by the possibility to have those needs met.”¹⁸⁴

¹⁸⁰ Ibid.

¹⁸¹ Ibid.

¹⁸² Ibid., 466-467.

¹⁸³ Ibid., 467.

¹⁸⁴ Ibid.

I agree with Kittay that dependency needs should not be seen as interfering with one's opportunity to flourish, but I do think that some kind of independence has to be realized in order to be able to flourish regardless of one's dependency needs.

Malcolm Richardson recognizes that people with disabilities may conceive of independence as being compatible with being dependent on care of others. "Independence then is about personal power and control over one's life rather than doing things for yourself, unassisted."¹⁸⁵ Richardson proposes that the nursing practice should be based on alliance between nurses and people with disabilities. This seems to be a useful understanding of how the care-relation can take shape. If people with disabilities and caretakers are allies in the realization of care such that the care is the product of cooperation between the caretaker and the disabled person, then care can be both based on mutual recognition and having control over one's own life.

The caretaker has to take the choice of the disabled person as guiding in the provision of care, recognizing the equality of the disabled person as someone who should not be subordinated to the choice of others. Then, together the caretaker and the disabled person have to find the best way to give shape to the choice of the disabled person in the provision of care. Here the disabled person also has to recognize the caretaker as an equal person cooperating in the fulfillment of the need for care of the disabled person. Thus the disabled person and the caretaker work together in the realization of the dependency needs of the disabled person. This solution for bringing the care-relation in accordance with the recognition of both the caretaker and the care receiver coincides with how Fraser envisions the establishment of recognition in parity of participation. It can also be led back to Anderson, who argued equality takes shape in participation with others. By understanding the care-relation as part of an activity that involves two participants it is possible to understand how both parties involved can be recognized as equals. Recognition of the care receiver and the caretaker as equals entails not excluding one of them from participating as a peer in the care-relation (this is the *participation principle*).

¹⁸⁵ Malcolm Richardson, "Addressing Barriers: Disabled Rights and the Implications for Nursing of the Social Construct of Disability," *Journal of Advanced Nursing* 25 (1997) 1269-1275.

By introducing the notion of participating as peers with regard to the care-relation the same kind of problem as was discussed in the first two chapters seems to rise again, because some people with severe disabilities are not be able to participate as peers in the care-relation.

A description of the caring relation as a cooperation between the caretaker and the care receiver is not in line with how Kittay describes dependency relations in *Love's Labor*. For Kittay the dependency relation, which is the relation between the caretaker and the care receiver, is one in which the caretaker is the one primarily responsible for the wellbeing of the one depending on care. The dependent or charge, as Kittay calls it, does not even have the ability or entitlement for committing or entrusting the responsibility for the care for her own wellbeing to the caretaker.¹⁸⁶ This, according to Kittay, has to be done by a third party.¹⁸⁷ Kittay's description of the dependent does not indicate that she considers the possibility of mutual cooperation between the caretaker and the one depending on care based on the choices made by the dependent. This could be due to the kind of care and dependents Kittay envisions. She is only concerned with care for people who do not have the abilities necessary for any kind of mutual cooperation such as babies or people with severe mental disorders. This makes it understandable that she sees the caretaker as the one being in charge of the wellbeing of the care receiver, and that there is no mention of cooperation.

It is important to be aware of the difference between taking care of someone who only has a physical or mild mental disability and taking care of someone with little mental capacities. Where the fist kind of care can take the shape of an alliance between the person with a disability and the caretaker the second one cannot. In what follows I will be primarily concerned with the first kind of care.

The kind of independence described above as having control over how one's care is provided can be realized in an inclusive way as the caregiver and care receiver recognize each other as equal persons and situate themselves as allies. Still the caregiver has to be transparent to the needs of the care receiver, which means putting

¹⁸⁶ Eva Feder Kittay, *Love's Labor*, 31.

¹⁸⁷ *Ibid.*

her own desires, aspirations or wishes aside for the moment. Because the caretaker is a person situated in a broader context than that of caring it can happen that at certain moment the caretaker is unable to be transparent to the care receiver because she needs to attend to her own needs. At such a point the care receiver is likely to become a subjected to the choice of the caregiver. To avoid this, another kind of independence has to be realized, namely, the care receiver should not be solely dependent on one or a few particular persons for having one's need for care met.

The disabled person should have different options for getting dependency needs met, in order to be able to escape a situation in which she is subordinated to the choice of others.

Also from the point of view of the caretaker it is important that the disabled person is not solely dependent on her because she can too experience the caring relation as suppressive when she is not recognized as an equal. When ending the caring relation would mean that the disabled person would not get the necessary care this would put moral constraints on the caretaker not to end the caring-relation. And that may result in continuing a situation in which she is not recognized as an equal person. This is also of concern for the situation in which one takes care of persons with very severe mental disabilities, because then the care tasks, as Kittay points out, can be so demanding that the caretaker is not able attend to her own needs.¹⁸⁸ Being trapped in such a caring relation also testifies of society not recognizing one as an equal who's needs should be taken into account.

In order to prevent that disabled people who depend on care of others end-up in a caring relationship in which they are subordinated to the choice of others, requires that society takes responsibility for providing care for the disabled. If one does not have the resources to buy independence by providing oneself with different options for having one's dependency needs met, one is easily subjected to the beneficence of others. If one is dependent on beneficence one may have to subject oneself to the choice of others because otherwise one risks that the care is not provided, and that constitutes the caring relationship that Silvers opposes to. Only when the state organizes a care system can it be guaranteed that people are not dependent for care on

¹⁸⁸ Ibid., 65.

one (or a few) particular person(s) as their only option for getting their needs for care met. If one is dependent on the state, one is not dependent on the choice of another person as I have argued elsewhere with reference to the *Metaphysics of Morals* from Immanuel Kant.^{189,190} The state has to ensure that people with disabilities have freedom of choice in who provides their care. This can take shape in different ways.

But as the opportunity of having a way out of a caring relation may prevent people from being trapped in a suppressive situation, it may not be helpful with ensuring that there are caring relations in which both dependent and caretaker are recognized as equals. This also requires attention, because otherwise there is no real way out of the suppressive situation because ending one suppressive caring-relation may for the disabled person mean having to start a new suppressive caring relation. As described above the caring relation as a cooperation between the caretaker and the care receiver is a relation in which both can be recognized as equals and in which the care receiver can acquire independence. The state has to take this into consideration as well when taking concern for the providence of care to citizens in need.

From the discussion of the care-relation with regard to the recognition of *equality principle* three guidelines for the organization of care in an inclusive way can be abstracted. First, care should be organized in such a way that it supports the establishment of the care-relation as a cooperation between the care receiver and the caretaker. Second, both the care receiver and the caretaker have to be able to end the care-relation when one of them is not recognized as an equal, without the one depending on care then being deprived of options for getting her needs met. Third, the state should take responsibility for the providence of long-term care.

6.1.2. What is Required of Care in Order to be Compatible with the Participation Principle?

The *participation principle* already came to the front when discussing the care relation. But this principle also plays a different role with regard to the organization of

¹⁸⁹ Yuki Tol, "The Innate Right to Freedom and the State's Duty to Provide Assistance for its Citizens with Physical Impairments," ms. 2014.

¹⁹⁰ Immanuel Kant, "The *Metaphysics of Morals*," *The Cambridge Edition of the Works of Immanuel Kant*, trans. and ed. Mary J. Gregor 360 - 603 (New York: Cambridge University Press, 1996) 458 / 6:314.

care. Care should be organized in such a way that it does not exclude people with disabilities from participating as peers in society. This means that it should be organized in such a manner that it is compatible with people with disabilities participating in society.

First of all this means that it should not be solely centered around one location where people are supposed to spend their every day of their life. As was argued in the previous chapter being able to participate means that one has to be able to be present at the site a particular practice takes place. If care is organized around one particular location this excludes people who depend on care from participating in practices in society such as education, labor or leisure time activities.

This is also important for people who have such severe mental disabilities that they cannot decide for themselves that they want to go somewhere. They should be recognized as equal members of society who are for example are part of a family. Not being excluded from participating in family life for them can mean being able to go to birthday parties or join their family on holidays. This means that the care they require should not exclude them from taking part in such activities.

Second, it has to be compatible with a certain amount of flexibility that participation as a peer in society requires. Especially in social activities it is difficult to schedule care in advance. Being tied to a care schedule may make it impossible to participate in social activities. When it is not the disability that requires tight care schedule but it is the care-provider that demands a tight schedule, people depending on care may be excluded from participating as peers in social activities. Thus, care should be provided in a sufficiently flexible way as to be accommodative to participation in difficult to schedule activities.

Again this may also be of concern for people with such severe mental disabilities that they are not able to decide to participate in social activities. Their being part of a community or family means that they may be included in social activities that require flexibility by the other members. This should not be obstructed by the way in which their care is provided because that results in their exclusion.

The *participation principle* can be used as well as a guideline for the organization of care, the organization of care should not exclude one from participating as a peer in

society. Two aspects are primarily of importance with this regard, first, that care is not provided solely on one location and second, that it is sufficiently flexible time wise.

6.2. Personal Assistance Model

In this section it will be discussed whether the personal assistance model for providing long term care fits with the requirements of inclusion. Shakespeare describes this model as follows:

Personal assistance (PA) refers to the new ways of delivering personal support in daily living, which were devised by disabled people's movements in Britain, North America and Northern European countries from the 1970s onwards, as an alternative to traditional models of care [...]. Personal assistance was a key element in the empowerment of people with significant impairments, who had previously depended on residential care. Rather than living in institutions, or being supported in the community by paid carers supplied by the state, or being reliant on family and friends, disabled people began to receive payments directly to manage their own staff through arrangements such as the Independent Living Fund.¹⁹¹

It is highly relevant to discuss this model as in recent long term care reforms in several European countries the personal assistance model has become available to people with disabilities. Therefore it should be discussed whether this reform is an improvement with regard to inclusion of people with disabilities.^{192,193}

In this section it will be discussed whether the personal assistance model for organizing long term care based on a direct payment scheme is in line with the guidelines for organizing care in accordance with the *recognition of equality principle* and the *participation principle*. According to this model, people with disabilities who depend on care are provided financial resources in order to organize their own care. The direct payment scheme enables people with disabilities to employ their own

¹⁹¹ Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 173.

¹⁹² Emmanuele Pavolini and Costanzo Ranci, "Restructuring the Welfare State: Reforms in Long-Term Care in Western European Countries," *Journal of European Social Policy* 18 (2008) 246–259.

¹⁹³ Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 174.

personal assistants who perform the care tasks. Shakespeare indicates that the Swedish pioneer in personal assistance Adolf Razka thought the most important features of this way of providing care were “that the disabled person chooses who works, with which tasks, at which times, where and how.”¹⁹⁴

It will be argued that the PA model based on direct payment does make true the expectations with regard to flexibility in time and location, but it also has some disadvantages. It will be discussed whether the advantages are due to the employer-employee relation in which the care is provided. Furthermore the most important disadvantages of a PA model based on direct payment seem to be met by home care organizations.

It will be questioned whether the success of the PA model based on direct payment may be due to there being no third party involved in the caring relation, such as there is a third party, for example the home care provider, involved in alternative models for providing long term care.

6.2.1. *The Employer/Employee Relationship*

One of the main features of direct payment is that the care receiver is the employer of the caregiver. This might give the disabled person a more powerful position in relation to the caregiver than would otherwise have been the case. But as Clare Ungerson suggest the relationship between the personal assistant and the person with a disability differs from a common employer/employee relationship because the one depending on care is more vulnerable than an employer usually is. So the relationship has to be one of trust as well as Ungerson points out.¹⁹⁵ Furthermore, as Shakespeare argues, it is a relationship that involves feelings.¹⁹⁶ According to Shakespeare the relationship between the care receiver and the caretaker is not likely to fit the ideal of Independent Living movement as the personal assistant being the arms and legs of a person with a disability.¹⁹⁷

¹⁹⁴ Ibid., 175.

¹⁹⁵ Clare Ungerson, “Personal Assistants and Disabled People: an Examination of a Hybrid form of Work and Care,” *Work, Employment and Society* 13 (1999) 588.

¹⁹⁶ Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 173-187.

¹⁹⁷ Ibid., 175.

Still, Shakespeare points out that within the PA model the personal assistant can be denied the recognition as an equal by the care receiver. The relationship can take the shape of a more traditional master servant relation, in which the personal assistant for example only speaks when spoken to.¹⁹⁸ There are records of personal assistance “being abused and exploited and treated with disrespect.”¹⁹⁹ But this is not very common as Shakespeare describes relationships between caretaker and care receiver within the PA model that testify of recognition of equality as well.²⁰⁰ For example the relation can take the shape of a professional friendship that is experienced as a relation in which the care receiver and caretaker are equals.²⁰¹ The variety of relations that occur within the PA model makes it difficult to judge whether the PA model lives up to the *recognition of equality principle*. There is no guarantee that this is the case within the PA model. On the other hand, the PA model leaves ample room for the relation between the care receiver and the caretaker to be one in which the both are recognized as equals.

Another aspect of the employer/employee relation is the power to hire and fire that lies with the care receiver. This suggests that the relation is easily ended when it becomes repressive. But this may not always be the case as will be explained. Ungerson did research different ways in which direct payment for hiring personal assistants is organized in different countries.²⁰² She found that the care-relations take different shapes in the different countries with regard to emotional attachment involved. In some countries people were allowed to hire close relatives resulting in more ‘warm’ (emotional affective) relations. The affection involved makes these relations last longer but they are also more difficult to end. She found that when personal assistant were recruited by professional agencies who also take responsibility for replacement, the relationships were more professional, involved less affection and were easier to end.²⁰³

It can thus be argued that the employer/employee relationship does not necessarily provide the opportunity to easily end a caring relation although the power

¹⁸² Ibid., 181.

¹⁹⁹ Ibid.

²⁰⁰ Ibid., 182-185.

²⁰¹ Ibid., 182.

²⁰² Clare Ungerson, “Care, Work and Feeling,” *The Sociological Review* 53 (2005) 188–203.

²⁰³ Ibid.

to hire and to fire is with the person with a disability. Other factors such as emotional attachment play a role.

The finding that more professionally organized PA relations are more easily to end can be seen as an argument in favor of such an organization. But organizing care in a way that is accommodative to the situation of a person and the practices in which a person participates can make that hiring someone with which the care receiver already has an emotional relation is preferable.

For example in the Dutch television program JZHMH the story is told of Frank, a young man with cerebral palsy who lives in a students home in which he hires his friends and roommates to provide care.²⁰⁴ This enables him to participate as a student in the informal setting of a student's home. One can imagine that if Frank would not be able to get care of this roommates but professional caretakers were coming around to help him, for example with eating dinner, this might interfere with the practices taking place at the students home, especially when the caretakers are much older than Frank.

But would it not be preferable if Frank's roommates helped him for free? Would this be the case, Frank would be dependent on the charity of his friends, furthermore he might not feel free to make more demanding claims he may be able to make because of the payment being involved. For example, his roommates have to live by a schedule in order to ensure that there is always someone available to assist Frank.

6.2.2. Flexibility in order not to Exclude people from participating as peers

Angie Carmichael and Louise Brown indicate that people with disabilities making use of personal assistance based on direct payment schemes have more control over the organization of their care and feel more satisfied about the care they receive in comparison to people who receive directly provided care.²⁰⁵ Furthermore, they point out that with the help of personal assistance paid from direct payment schemes

²⁰⁴ "Je zal het maar hebben," episode broadcasted first on 4 March 2014, http://www.npo.nl/je-zal-het-maar-hebben/04-03-2014/BNN_101342899, viewed July 2014.

²⁰⁵ Angie Carmichael and Louise Brown, "The Future Challenge for Direct Payments," *Disability & Society* 17 (2002) 799-800.

they did gain more flexibility that enabled them to participate in society and fulfill parenting responsibilities.²⁰⁶

Also, Caroline Glendinning e.a. point out that people employing their own personal assistants experience control, flexibility over who provides care and how it is provided. They also express that people employing their own personal assistants are able to participate in activities outside their home.²⁰⁷

Moreover, Askheim's research supports the above findings about the organization of care with personal assistance paid from direct payment schemes.²⁰⁸

At the points of flexibility in time and location as not to exclude people from participating as peers in society the PA model based on direct payment seems to meet the requirements of an inclusive arrangement of long term care. The model also gives the people depending on care control about their care as can be learned from the empirical research referred to above.

The PA model does meet the *participation principle* as it allows for the organization of care in a way that is flexible with regard to time and place which makes that people are on this ground not excluded from participating as peers in society.

6.2.3. *Barriers of Administration and Recruitment*

One of the disadvantages of the PA model based on direct payment is the administration that comes with it. As Carmichael and Brown indicate “[f]or some people, however, the time and complexities involved in the administration of using a direct payment acts as a deterrent and so they continue to opt for directly provided services.”²⁰⁹ This means that for people who consider the administration to be too burdensome the PA-model based on direct payment is not an option. Another disadvantage is that it can be difficult and demanding to find personal assistants.

²⁰⁶ Ibid., 801-802.

²⁰⁷ Glendinning, Caroline e.a., “New Kinds of Care, New Kinds of Relationships: How Purchasing Services Affects Relationships in Giving and Receiving Personal Assistance,” *Health and Social Care in the Community* 8 (2000) 201–211.

²⁰⁸ O.P. Askheim, “Personal Assistance for Disabled People – the Norwegian Experience,” *International Journal of Social Welfare* 8 (1999) 111–119.

²⁰⁹ Angie Carmichael and Louise Brown, “The Future Challenge for Direct Payments,” 802.

Glendinning e.a. suggest that “[m]any direct payment users had experienced difficulty recruiting suitable staff.”²¹⁰

Difficulties with recruiting staff may form a barrier for people to ending a contract with a caretaker.²¹¹ Being able to end the caring relation was one of the requirements of organizing care in an inclusive way. The PA model based on direct payment may not score as good on this account as might be expected at first sight as in practice people may find it difficult to recruit a new caretaker. This can also be interpreted as the provider of care (the state) failing to offer the care receiver sound options for getting one’s need for care met by someone else.

The two disadvantages of administrative burden and recruitment make the PA model based on direct payment unfit for people who cannot take the burden of the recruitment and administration. Thus, the direct payment scheme cannot be the sole way in which care is provided in society. Now one can question whether the direct payment is necessary for the organization of personal assistance in such a way that it is compatible with the requirements of inclusion. A homecare provider can take away the burden of administration and recruitment and thus provide more accessible care. But how does that affect the relation between the caretaker and care receiver?

6.2.4. The Involvement of a Third Party in the Care-Relation

An aspect of the PA model based on direct payment that comes with the employer/employee relationship is that there is no third party involved in the relation between the caregiver and the care receiver. The organization of care in this model is something that is between the caregiver and receiver. This may make it more likely that the providence of care takes the shape of an alliance between the caregiver and care receiver. A third party such as a homecare provider may one-sidedly impose demands and rules upon the caregiver and care receiver as this party is the most powerful of the ones involved. For instance, a homecare provider may impose rules with regard to the amount of time that may be spent on the providence of a particular

²¹⁰ Glendinning, Caroline e.a., “New Kinds of Care, New Kinds of Relationships: How Purchasing Services Affects Relationships in Giving and Receiving Personal Assistance,” *Health and Social Care in the Community* 8 (2000) 206.

²¹¹ Clare Ungerson, “Care, Work and Feeling,” *The Sociological Review* 53 (2005) 201.

care task. These could be reasonable and not obstructive to the care-relation between the caregiver and care receiver but they may as well be in conflict with the requirements of organizing care in an inclusive way. It is important that the organization behind the caregiver embraces the guidelines of organizing care in an inclusive way and thus is responsive to both the caregiver and the care receiver. The transparency that is required for the providence of good care should somehow be adopted by the homecare provider. Furthermore, the homecare provider should become a partner in the cooperation between the caregiver and the care receiver and recognize both of them as equals. This may pose a challenge to the contemporary homecare providers who may not be used to such a way of relating to the providence of care. In theory it should not be impossible to realize the care provided by a homecare provider in an inclusive manner and thus proving that the PA model is not the only model that is able to meet requirements of inclusion. However, it remains an open question whether it will be successful in practice.

What could be an advantage of a third party being involved in the care relationship is that the third party can see to it that the caretaker and care receiver are not subordinated to the choice of the other and that both are recognized as equals. Some monitoring on the provided care is missing in the PA model based on direct payment. The caregiver and care receiver are both expected to be able to end a suppressive relation by themselves. But in case one of them is unable to do so the suppressive relationship might continue unnoticed. A third party might prove helpful in such a situation to empower the suppressed party to end the relationship.

6.3. Conclusion

As I have argued above, the providence of care should be compatible with the recognition of both the one cared for and the caretaker as equal persons. Which requires that the care-relation takes the shape of a cooperation between the caretaker and care receiver. Secondly, both the caretaker and the care receiver should be able to end the relation. And thirdly, the state should take responsibility for the providence of care.

In order to be compatible with the *participation principle* care should be organized in a flexible manner with regard to time and place. The PA model scores very good in relation to the *participation principle*.

The PA model can be in line with the *recognition of equality principle* as the care-relation within this model can be one in which both parties are recognized as equals. But this is not necessarily the case as empirical studies point out. Furthermore it might be more difficult to end the care-relation within this model than it seems from the outside. The emotional involvement that may exist between the caretaker and care receiver can make it difficult to end the care relation. Finally the state may not take full responsibility with the PA model for providing care in an inclusive way as problems with recruitment can make it difficult to end a care-relation and in a way the state does thus not live up to the requirement that care receivers should have other options to have their needs for care met.

The administrative burden is another point that makes the PA model not accessible for all in need of care. It is thus important to note that organizing care in an inclusive way cannot solely take shape in the PA model based on direct payment. This does not mean that the PA model should not be an option for some people to get their need for care met. But one should be aware that other inclusive ways for providing care have to be available. Because people unable or unwilling to take the responsibility of organizing their own care are still entitled to receiving care in an inclusive way and the PA model is unfit to provide that for these people.

For people who are able to organize their own care the PA model proves to be in compliance with the *participation principle* as they are able to organize their care in a flexible way with regard to time and place.

Overall the PA model can be a way for providing care in an inclusive manner but because it is not fit for everyone effort should be taken to develop other ways of providing inclusive care.

7. Conclusion

The main question of this thesis is: *what does inclusion of people with disabilities in society mean?* This question has been answered by developing an account of inclusion that is applied to the position of people with disabilities in society. It became clear that inclusion of people with disabilities in society is about how society as a whole and the individual citizens relate to them. The attitudes people have towards people with disabilities have to be inclusive for inclusion to be realized. This is something that lies with the individual. But creating the enabling structures to support the opportunity of people with disabilities to participate as peers is something that can take shape only by people acting collectively. Being included means that the principles of inclusion are fulfilled.

The *recognition of equality principle* states that in order to be included one should be recognized as an equal by the members of the group one is included in. The inclusion of people with disabilities in society thus means that they are recognized as equals by other citizens. The *participation principle* states that one is included if one is not excluded from participating as a peer. The inclusion of people with disabilities in society thus means that they are not excluded from participating as peers. This entails that society takes care to support everyone in acquiring the capabilities one needs to participate as a peer. The *needs principle* reads that in order to be included one's needs have to be taken into account. The inclusion of people with disabilities in society thus means that their needs are being taken into account.

The fulfilment of the three principles of inclusion at a society level requires that inclusion is realized socially, physically and politically. Social inclusion means that the attitudes of people with disabilities attest of one's recognition as an equal, that they are not excluded from participating as peers because of prevailing social attitudes towards people with disabilities and that the attitudes others have towards people with disabilities does not interfere with their needs being taken into account.

Physical inclusion means that the physical environment is in accordance with the recognition of people with disabilities as equals, that it enables people with disabilities to participate as peers and that in the design the needs of people with disabilities have been taken into account.

Political inclusion entails the recognition of all members of society as equals who should be involved in decision-making. It has to be ensured that no one is excluded from participating as a peer in political debate, by allowing for different kinds of rhetoric. Also, everyone's needs have to be taken into account, this requires that everyone should have the opportunity to communicate needs. This can be ensured for instance by acknowledging narrative as a mode of communication in political debate. Political inclusion also has to do with how the concern for the need of all members of society takes shape. It may not always be possible to fulfill everyone's needs. Political inclusion enables a decision-making process in which difficult decisions about conflicting needs can come about.

Inclusion of people with disabilities in society takes shape when they are socially, physically and politically included. When the inclusion of people with disabilities in society is realized not all issues concerning disability will disappear. For instance some people with disabilities require care of others in order to attend to their needs. The organization of care can be done in an inclusive way when the principles of inclusion are taken into account. This means that the care-relation has to be an alliance between the caretaker and care receiver. Furthermore the state has to ensure that people depending on care do have different options for having their needs for care met. Besides, offered care should be sufficiently flexible with regard to time and place.

The personal assistance model based on direct payment as way to provide long-term care has been evaluated in relation to the principles of inclusion. It is a way of providing care in an inclusive manner but is not suitable for everyone.

With this thesis I have pointed out that based on everyone's equal moral worth people with disabilities should be included in society, I have explained what inclusion means and how social, physical and political factors are important for the inclusion of people with disabilities in society. I think it became clear that including people with disabilities in society is something that is of concern for society as a whole, it is not something that can be realized top down by the government. Both people's attitudes toward people with disabilities and the physical environment have to be in line with inclusion as well. Nevertheless politics does play an important part in realizing

inclusion because within politics inclusive policies can take shape. At the introduction I said that inclusion might constitute the final goal disability rights activists strive for. I think this is true but that does not mean that realizing inclusion means that they can retreat from playing an active part in articulating problems people with disabilities face. Inclusion exists only by the grace of communicating different perspectives in order to be able to organize matters in accordance with the inclusion of all people in society. Documentaries have to be made about the lives of people with severe disabilities, people with rare conditions do have to make their needs known to others in order for their need to be taken into account, and with every change in society people with disabilities have to explain how this might affect them. This is an ongoing process as long as society keeps evolving. Inclusion thus is a dynamic process that requires people to continuously remain responsive to one's fellow citizens.

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