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# 1

## A Different Light on Normalization: Critical Theory and Responsive Evaluation Studying Social Justice in Participation Practices

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### Abstract

*Responsive evaluation provides guidelines to include various stakeholders in dialogue. However, a substantial theory to understand power asymmetries and inequalities is lacking. The purpose of this article is to consider which theoretical framework for societal critique can be helpful to evaluate practices in relation to social justice. These questions will be addressed using fragments from a responsive evaluation study on the involvement of people with an intellectual disability in public policy. Our study shows that Foucault's framework on normalization was helpful. It revealed that the engagement and striving for equality and social justice can turn out to be disciplining itself. © 2015 Wiley Periodicals, Inc., and the American Evaluation Association.*

Social justice has been explicitly addressed as a concern in the evaluation literature (Greene, 2006; Mertens, 2009; Schwandt, 1997). Responsive evaluation is an approach that aims to enhance the mutual understanding between stakeholder groups and value-driven transformations (Abma, 2005; Abma & Widdershoven, 2011; Guba & Lincoln, 1989). Responsive evaluation takes into account the issues and voices of as many

stakeholders as possible, as well as those who are less heard in policymaking. It is an interactive, reflexive process on the meanings and values of a practice with and among all groups whose interests are involved. This is stimulated by dialogue between the different stakeholder groups. Dialogue is a learning process oriented toward mutual understanding (versus a debate focused on strategic action). In dialogue, people meet each other as persons with a name and face (and not as parties in a debate).

In responsive evaluation, the evaluator should create a power balance between the various stakeholders, leveling power differentials among groups. The empowerment of marginalized groups is in some sense an extension of this (Baur & Abma, 2011; Mertens, 2009). To level out the influence of all stakeholders, most of the time it is necessary to support the weaker voices. In the absence of the evaluator's advocacy for minority group interests, majority elite views can dominate (House, 1993).

Methodologically, responsive evaluation provides guidelines to include various stakeholders and to reckon with power differentials. Stakeholder groups are first consulted separately; a phase of collaboration and dialogue to share stakeholder issues then follows. The evaluator acts as an interpreter of stakeholder issues, a process facilitator for the dialogue, an educator to foster mutual understanding, and a Socratic guide who evokes reflection on taken-for-granted issues. However, there is no substantial theory to elucidate power asymmetries and inequalities. Critical theory can be helpful in interpreting power issues and in shining a light on social justice in the practice that is evaluated.

We draw on Foucault (1982, 1984, 1989, 1997) to explicate power issues. Foucault maintained that economic and political demands dominate in today's society. These demands dominate people through discipline and principles of *normalization*. The goal of this discipline is to make citizens politically obedient and economically productive. Norms are embedded in discourses, and these discourses reflect and reestablish hierarchies in societies. Power issues are at stake here. Indeed, when people do not meet the ideal norms, they are excluded. Foucault argued that it is important to unravel these processes of normalization, because defining the norm leads to processes of inclusion and exclusion. Power issues in organizations can be studied from this point of view in order to shed light on social justice.

## Method

The focus of the presented responsive evaluation was the participation of people with intellectual disability (ID) in policy-making, education and research. In this project, which took place over 18 months in the Netherlands, we wanted to know the conditions necessary for people with ID to participate and how the environment can be more open and inclusive to allow the voices of people with ID to be heard.

To find answers to these questions, we selected three different participation practices in which people with ID already participate. One of the practices involved was the participation of people with ID in policy making in client councils of a health care organization: De Regenboog (the name is a pseudonym). This practice is the focus of this article because it provides a good case for learning and shows our use of critical theory to interpret participation practices.

The responsive evaluation approach was chosen to increase the personal and mutual understanding of the particular situation of participation. Therefore, we included as many stakeholders as possible: people with ID and coaches, managers, and parents of people with ID from the health care organization. Evaluation activities included interviews (structured and open), participant observations, and focus groups. We interviewed 10 clients with ID who participate in the client councils, two parents of clients with ID, six coaches and two managers. Topics included experiences of members in the client councils, the meaning of participation in the councils, and having a voice. Participant observations included six client council meetings. In the collaboration phase, one focus group was held with all the coaches at De Regenboog. Finally, one mixed focus group was organized with professionals and clients that included participants from the three evaluation sites. An inductive thematic analysis revealed the issues of the various stakeholder groups. In a secondary analysis, these issues were related to the framework of Foucault.

We were aware of the power imbalance between the stakeholders, and wanted to give voice to those in a more vulnerable situation—in this case, the people with ID, who were care dependent. We decided to work together with people with ID in our own evaluation team. Including people with ID meant they could bring in their own experiential knowledge, and hierarchic relations between evaluators and researched could be redressed (Nierse & Abma, 2011; Oliver, 1992). They could also relate to other people with ID and make it easier to gain access to the practices and people we wanted to contact and talk to.

### **From Theory to Practice: Setting**

De Regenboog is an organization in the Netherlands that provides care and support to 2,200 people with ID, as well as to their parents. De Regenboog values the involvement of clients with ID in their organization. Besides normative arguments of rights and justice (clients must be able to have a say and raise their voice), the organization has to meet legal demands concerning client councils. Since 1996, the involvement of clients in care organizations is supported by law in the Netherlands (this law is named *Wet Medezeggenschap Cliënten Zorgsector*). This law is based on the idea that the daily experiences of clients should inform the board of directors of care institutions and that decisions of the board should match

client input. In this way, clients have a say in decisions that influence their lives.

In Regenboog, clients in a council regularly gather to discuss a variety of issues. Issues can be brought up by management, because legally they have to get advice from the client council about certain policy issues (such as safety plans, food, and year plans). Clients can also bring in issues to discuss.

Clients get support to learn to fulfill their role in the client council. The organization also developed supporting material to structure the meeting, like a guideline with pictograms and a gavel for the chairman. One of the clients fulfills the function of the chairman and notes are made. This structure gives support to the clients. They know what to do in which order, and the materials are accessible and understandable for them. In a constructive way, the organization has tried to make the formal framework of a meeting accessible for people with ID.

Clients are also supported by a coach (a professional from De Regenboog). The coach can help with practical issues such as making notes, getting into contact with managers, and helping to supply transport for clients between locations. In addition, coaches try to make issues and policy understandable for clients. They also help the client council determine their position in relation to the questions about policy measures that are submitted to them from management. Finally, the coach also monitors the structure of the meetings.

## Findings

### Clients

The clients who participate in the client councils value their roles. Being a member of the client council means taking on a social role, and it is a way to open up their horizons. It feels good for them to be part of a group, and participation gives them the opportunity to learn new skills. The value for the clients lies mostly in the participation itself and feelings of “belonging.” A client council member explained:

The client council, what I do . . . Just attending the meeting and talking. I'm not there on my own; we are with four or five of us. I mainly do it to attend and be there. (Member)

Client council members do not explicitly express the value of having a say or having a voice and influence on decision-making processes in the organization. Some of them—mainly clients who have been in the client council for a longer time—do value the fact that they can express themselves and voice concerns of other clients.

I think it's important to speak up for the ones who live here. It means that I have a say and that I can help to decide. It's important to speak up in the group. You have to make clear what you want. (Member)

They value the supporting materials, and all clients think that the support of the coach is essential; they cannot do the job without their help.

Without the coach it will be a mess. We could not have this meeting without the coach. We wouldn't know where to start and who would make the notes?  
(Member)

But the coaches are not only important for the structure during the meeting; they also help to interpret what a client member brings in:

The coach has to understand us. When one of us cannot express what he means, the coach can explain what he means. (Member)

## **Coaches**

To enable the participation of clients in the client council, the role of the coach is crucial. As expressed by the clients, coaches create structure. In fact the coach builds a bridge between the management of the organization and the clients.

In practice, the coaches feel tension. They have to make issues accessible and understandable for clients, but they do not want to guide them too much. The line between enabling clients to make up their own mind and influencing them sometimes feels blurred. A coach:

Sometimes I see that people do exactly what you bring up. In fact you have to help them to structure and give them a framework otherwise you have nothing. That's really a tightrope.

Another coach also expresses the tension she experiences:

They want to be treated in a certain way, like adults and they don't want to be carried on the hand. But abstract issues are very difficult to understand. Because abstract thinking, that's difficult for them, at least, that's part of their disability. Finding this balance is sometimes difficult.

## **Manager of Client Participation**

The manager of client participation states that the participation of people with ID has undergone tremendous development. She refers to the situation where people with ID were locked away in institutions and their disability was a taboo for society:

While in the past they didn't have a voice and were not involved, today opportunities are created to make it possible to participate and to raise their voice. This development has been a struggle and it still goes on.

She is proud of what is made possible in the organization. People with ID are involved at diverse levels. Both the managers and the board of the organization value this participation. From her perspective, participation is not just organizing and giving instruments for involvement; it is about “the input of the other person, about the meeting of person to person.” This makes involvement an ethical issue relating to the realm of proximity between self and other. She refers to this as a “precarious process” that is under pressure in times of financial cuts.

### **First Analysis and Reflection**

Looking at the practice of involving people with ID in the client councils, one could argue that all formal requirements for a client council are met. More than that, the councils are actively supported. Time and money are spent on this, and an effort is made to make the councils accessible to clients and clients accessible to the councils. Clients value their role; it offers them new opportunities and broadens their horizons. The question is whether this approach leaves enough room for the experiences of the clients themselves and the values in their lives. The issues that are discussed in the councils can be very abstract and hard to understand and reflect on. The coaches experience tension: They support the clients to make up their minds and to formulate answers to policy questions. At the same time, they do not want to be too decisive. They have to discuss certain policy issues due to legal demands, but these issues can be very difficult.

When we look at the fulfillment of the chairman role, we see that the guidance of the coach is needed. In fact, the coach structures the meeting and coordinates all activities. The role of the chairman becomes a symbolic one. This is a complicated issue, because the people with ID who fulfill this role are proud to be able to do so. They feel recognized. The meeting minutes play an important role during the meetings. It takes a lot of time to go through the paperwork, and not everybody receives the minutes before the meeting. Some clients need the support of staff to read and understand the notes. It seems that the notes fit the formal framework, but that in practice the value of the content is insignificant or even symbolic.

Tension is also experienced by the evaluators themselves, as expressed in their field notes and reflection sessions:

I'm impressed by what I have seen during my observations in the client council of De Regenboog. A lot of effort is made to let people with ID participate in the councils and involve them in policy. And I can see that the people with ID value what they do. It's important for them. And yet, afterwards I feel uncomfortable. Why do I have the feeling that no justice is done to people with ID? I recognized this discomfort in the book of a philosopher and mother with a son, Ramon, with Down syndrome, who wrote:

“Ramon is not a client council member. He cannot talk. But two of his friends are client council members. They can say ‘yes’ and ‘no.’ What they agree with is considered to be the outcome of a ‘democratic decision-making process.’ A lot of organizations correctly comply with policy that is based on autonomy as a general ideal for all” (Rondhuis, 2011, p. 91).

How does this all relate to what I see and experience? (Evaluator, the first author). “Your critical question stemming from uncomfortable feelings is situated in your body at that moment. You still haven’t words to analyze the situation. Yet, you acknowledge that these feelings and experiences have a right of their own and can function as a compass to search for different interpretations of what is going on in the studied practice” (Evaluator, the second author).

## **Dialogue**

The findings were difficult to discuss with the coaches, the coordinator of the department for client participation, and the manager of client participation. Although they were open to feedback, admitting the fact that people with ID have their limitations is a sensitive issue. Coaches deny feelings of tension or struggle and only make an effort to think about new ways to approach the involvement of clients with ID.

### **Taking a Closer Look: Secondary Analysis Through the Lens of Foucault**

Foucault argued that in today’s society there are informal, unwritten rules—the norms to which people have to conform in order to meet goals for political obedience and economic productivity. On the one hand, this leads to homogenization (everybody has to meet the same demands); on the other hand, it leads to exclusion. After all, not everybody complies with the unwritten standards and norms. According to Foucault, disciplining power created differences and hierarchies and processes of inclusion and exclusion.

Inclusion and exclusion are also highly debated themes in the field of disability studies (DS). An important aim of DS is to contribute to more social justice and equal rights for people with disabilities (Vehmas & Watson, 2014; Young & Quibell, 2000). Disabled people should have the same rights and obligations as other citizens. The viewpoint of DS is that disability is socially constructed, which means that it is the result of the way society deals with disabilities. People with disabilities are like everybody else. Society itself makes the difference. When society is more open and inclusive to people with disabilities, inequalities can be eliminated and social justice can be achieved. Aiming for normalization and social role valorization can contribute to this process.

In line with this thinking of the disability movement, professionals, family members and advocates of people with ID in De Regenboog take normalization of people with ID as a starting point to strive for more equality and social justice. From their point of view, the recognition of differences and disability is at odds with this striving for normalization. Making differences explicit leads to inequality and social injustice. In line with the disability movement, the organization has to include people with ID. It is up to society (that is, the organization) to be inclusive, make an effort to help people take on new social roles, and empower them. The societal norm that everyone has to be autonomous is not put under scrutiny.

However, Foucault argued that normalization is a way to discipline people. This discipline is a form of power to ensure that people meet the standards of what is “normal” in our practice; people with ID have to function as autonomous persons who are able to raise their voices and can form their opinions about policy issues (see McIntosh, 2002). Although coaches struggle with this norm in their work with people with ID, the difference (not being able to fulfill the norm) is not acknowledged. It is *not done* to recognize inabilities. But it is exactly this denying of difference that can lead to exclusion and social injustice, from the point of view of Foucault. Striving for normalization turns out to be an excluding process.

It is exactly this viewpoint of Foucault that enables me to interpret my feelings of discomfort when I observed the meeting of the client council. No effort is too much for the organisation to make it possible for people with ID to participate in the client council. But in order to achieve their involvement, people with ID have to fit in the formal framework of a client council meeting. They have to comply with the liberal norm of the free and autonomous individual who operates without help of others. From my point of view it is exactly this striving for normalization that does no justice to them. They are not valued for the unique persons they are. (Evaluator)

## Conclusion

In this article, we have shown how responsive evaluation can be helpful to study social justice. The methodology itself tries to overcome imbalance of power by including various stakeholders and by giving voice to marginalized voices and groups. By doing so, responsive evaluation offers the possibility to map the meaning and values of all stakeholders concerning the issues under study. This is not only about facts, but about the stories of the people involved, and the values that are of interest to them.

As we have shown in our research in the participation practice, a lot of effort was made to involve people with ID in the client councils. But still there were unsettling feelings and observations that justice was not done to people with ID in the studied participation practices. These embodied



experiences of the evaluator were taken seriously and encouraged us to search hidden norms. Applying the theory of Foucault provided us with the opportunity to better understand our own unsettling feelings and the practice under study.

Foucault's theory illuminated the disciplining effects of normalization and the limitations of rational communication. Together, these concepts complemented our understanding of social injustices in the participation practices of people with ID. These imbalances of power do not disappear easily. The evaluator can bring these power issues to the surface, and this may evoke and broaden the dialogue as new understandings brought up. Then it is up to the people involved to change the status quo. This requires an open mind to understand others' viewpoints, and a close look at one's own values (Abma & Widdershoven, 2011).

Reflection is also an important activity of the evaluator. Especially important is the recognition of the value of bodily resistance as a compass to search for new understandings of social justice and injustice. Based on such reflections, the evaluator can bring in the unrevealed processes of power and use the dis-ability to trouble societal norms and disciplining practices (Goodley & Runswick-Cole, 2014). to enrich and broaden the dialogue and mutual understanding.

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