

Living out participation. Growing in confidence and belonging

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► ABSTRACT

The Social Doctrine of the Catholic Church hinges on the principle of participation, inviting every member of the faith community to participate in the social processes and in favour of total social wellbeing. Persons with disabilities (PwD) cannot be exceptions to this invitation to participate, especially within the synodal process promoted in the recent times. This article proposes some ways through which the participation of PwD can be encouraged and supported in individual and social life and in the life of the church. This is done focusing on the development of self-determination skills, being in self-advocacy groups, claiming a positive disability identity, growing in competence relationally, and living out the sense of belonging.

► KEYWORDS

Advocacy; Empowerment; Identity; Persons with Disability; Self-determination; Social Doctrine of the Catholic Church; Synodality.

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Participation is a main principle of Catholic social teaching. The *Compendium of the Social Doctrine of the Church* points to how participation is expressed by activities through which a citizen, individually or in association with others, contributes to different aspects of their community, across social life areas. The compendium also mentions how necessary encouraging participation of those that are most disadvantaged is and how «since persons with disabilities are subjects with all their rights, they are to be helped to participate in every dimension of family and social life at every level accessible to them and according to their possibilities».¹

Participation-wise, the Synod of Bishops calls for the participation of all the baptized in a Synodal process that invites them to discern – together – how synodality can increasingly be lived out in the Church.² In this process of fostering synodality, which may be understood as an experience of being together on a journey, special care is called for towards groups that may risk being excluded, including people with disabilities.³

Considering the importance of participation and taking into account the synodal call just mentioned, I shall focus on two different layers the call is composed of: 1) Recognition of the risk of exclusion faced by people with disabilities 2) The actual participation of people with disabilities. The article will particularly focus on people with intellectual disabilities.

First of all, the synodal call includes an understanding that people with disabilities, together with other groups, risk exclusion. I shall point out how people with disabilities have often faced histories of marginalization, rejection, and oppression. An understanding of the past can, amongst other things, inform action-based planning for the future so that progress is made.

Secondly, the call encourages the participation of people with disabilities in the synodal process, which can extensively be seen as a call for their participation in the life of the church. The focus of the article will precisely be on participation of persons with disabilities in the church, which can be applied to the synodal process but is not limited to it. I will not seek to give an exhaustive exploration of participation but will rather provide points for reflection and action on

¹ PONTIFICAL COUNCIL OF JUSTICE AND PEACE, *Compendium of the social doctrine of the Church*, LEV, Vatican City 2004, n. 148.

² SECRETARY GENERAL OF THE SYNOD OF BISHOP, *Vademecum for the Synod on Synodality*, 2021, <https://www.synod.va/content/dam/synod/common/vademecum/en_vade.pdf>.

³A note on language: This article uses the term “disability”. The *Synod Vademecum* uses the term “handicapped” (2021, section 2.1, par. 3), a word that, as Andrews et al. point out, is «outdated and has largely been replaced by the term ‘disability.’ Whether person-first or identity first language is used, the term disability is widely used and universally accepted (i.e., World Health Organization International Classification of Functioning, Disability, and Health; National Institute on Disability and Rehabilitation Research; National Council on Disability)», E.E. ANDREWS et alii, #SaytheWord: A disability culture commentary on the erasure of “disability”, in «Rehabilitation Psychology» 64 (2019) 2, 111-118: 113.

ways in which participation, which can call forth confidence and responsibility both in the individual and in the church, can be lived out at different levels.

1. A history of oppression

Throughout history, people with disabilities have been one of the most marginalized and oppressed groups across different life domains and social milieus. In families, schools, workplaces, churches and other sites where cultures are created, people with disabilities have often been on the sidelines.

Although past interpretations of disability as a punishment from God or as the result of negative karma seem mostly (but not completely) a memory of the past, ramifications of it are still present today. Disability, in fact, is often treated with pity, contempt, or neglect, as if it is a reality that is “sad and bad.”

A brief look at history shows how much people with disabilities have been victims of violence and rejection. One can think of the children with perceived imperfections that were victims of infanticide in ancient Roman and Greek society, or the people with impairments that were publicly ridiculed and treated as objects of amusement at village fairs during the Middle Ages. In the 17th century people with disabilities were confined, together with other people deemed “strange,” in old leprosy houses. People with disabilities have also faced segregation through more recent forms of institutionalization. Many other examples from history tell of what people with disabilities have been victims of through the years. Oppression and stigma have often accompanied disability to this day.

Disability marginalization happens in various ways. Ableism, in both its more visible and more hidden or subtle forms, is very much widespread. Kwon and Archer write how «structural inequality in the form of ableism remains a fundamental force impeding the inclusion of people with disabilities»,⁴ pointing to ableism as conceptualized by disability studies scholar and activist Fiona Kumari Campbell, which defines it as «a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities».⁵

If many social structures are built giving privileged to the needs, experiences, and vision of people without disabilities, it is of no surprise that disability remains for a big part of the population something that is othered, as if it is an alien or exotic reality that pertains to “the other.” The process of “othering” sometimes happens in a subtle way. People with disabilities, for example, are frequently approached as the ones needing help, as passive recipients of people’s care, rather than active agents that can give and contribute to the communities they are part of. Every human being needs supports and every human being as something to give to the other, whether they have a disability or not. Although specific impairments do call for specific supports and aid, which is something that should not be denied or brushed away, this does not mean that the person

⁴ C. KWON – M. ARCHER, *Conceptualizing the marginalization experiences of people with disabilities in organizations using an ableism lens*, in «Human Resource Development Review» 21 (2022) 3, 324-351: 325.

⁵ F.K. CAMPBELL, (2009). *Contours of ableism. The production of disability and abledness*, Palgrave Macmillan, London 2009, 4.

in need of supports is only “in need” and is not able to support others! Narratives around disabilities have too often been monothematic, rather than rich and multi-layered?

2. Encouraging participation

Contrasting marginalization and encouraging participation, the synodal call⁶ asks for special care towards specific groups of people that may risk exclusion, including people with disabilities. The precise meaning of “special” care, however, needs to be clarified as something empowering rather than pitiful. “Special” care, in fact, should be a stance that makes an extra effort in recognizing the agency of people with disabilities rather than treat them as passive recipients of others’ good intentions.

Connecting church pastoral reflection and action with disability rights and advocacy movements, what are ways in which people with disabilities’ participation can be encouraged and supported not only in society on a general level but also in the church specifically? Although there are at least as many ways as there are people, this article will reflect on: developing self-determination skills, being part of a self-advocacy group, developing a positive disability identity, growing in competence together with others, and fostering community belonging.

3. Towards greater empowerment and self-determination

Disability rights movements have done a lot in helping to change policy as well as understandings and perceptions surrounding disability. For example, the Union of the Physically Impaired Against Segregation formed by Paul Hunt in 1972 in the United Kingdom, which helped give rise to the social model of disability that frames disablement as something that the social and structural context does to people with impairments,⁷ and the 1972 Center for Independent Living being established in Berkeley (California), also thanks to disability activist Ed Roberts, are just a couple of examples how disability activism and advocacy have helped change mental and socio-cultural structures regarding disability.

If in the past a lot of decisions that impacted people with disabilities were done by people without disabilities, the “nothing about us without us” motto that is connected to disability activism and that is included in the title of James I. Charlton’s seminal work emphasizes the importance of active participation in issues that impact one’s life.⁸

The development of thinking and practice around self-determination and empowerment is a sign that people with disabilities being protagonists of their lives and participants of society, as obvious as it should be, is not a side issue but

⁶ Cf. SECRETARY GENERAL OF THE SYNOD OF BISHOP, *Vademecum for the Synod on Synodality*.

⁷ Cf. M. OLIVER, *Understanding disability: From theory to practice*, Macmillan, Basingstoke (England) 1996.

⁸ Cf. J. CHARLTON, *Nothing about us without us: Disability oppression and empowerment*, University of California Press, Berkeley, CA 1998.

is of fundamental importance. Self-determined behavior is connected to the person acting autonomously.⁹ This does not mean that a person has no need of support, but it implies that there isn't so much external influence that the person's choice-making abilities are oppressed. Finlay, Walton and Antaki,¹⁰ in their study of residential services for people with intellectual disabilities, discuss of empowerment as promoting both choice and control.

Analyzing both self-determination and empowerment in their relational and social contexts, and therefore without over-focusing on individual agency as separate from the external realities individuals inhabit, Sprague and Hayes emphasize how «self-determination is the expression of a self that occurs within the context of empowering interpersonal and social structural relationships».¹¹

A person with Down syndrome who I shared community life with and who is very connected to her Catholic faith was a lector at the local Catholic parish she was part of. She expressed with enthusiasm how much being a lector at church mattered to her, but was also able to pull back from it when she didn't seem as interested in that role anymore. The staff that supported her in day-to-day life could help her process whether she wanted to continue being a lector or not, and why, and they were helpful in accompanying her to church so that she could participate at Mass that way, but it was up to her to ultimately make the decision as to whether she wanted to continue in the role or not. In church congregations, people with disabilities can be encouraged to make their own decisions in how they want to participate and contribute to the community.

Theologically, the notion of self-determination is not foreign to Catholic tradition. It is quite connected to the notion of conscience. Encouraging people to listen to and follow their conscience, while also forming it, is a fundamental teaching of the Catholic Church.¹² People are invited to listen to their unique conscience and, alongside others, live their lives following their unique path, making decisions by listening to their inner voice. Discerning the voice of conscience and developing self-determination skills is an intersection at which the church and non-religious realities can reflect together on ways in which people can be helped in growing confidently in their own choice-making.

4. Being part of a self-advocacy group

Being part of a self-advocacy group is one way of living out participation in the disability community and in society, and contributing to them both. Self-advocacy can be understood as speaking up (verbally or not) about the needs, rights, and preferences that one has. Self-advocacy can be closely connected to

⁹ Cf. M.L. WEHMEYER – N. BOLDING, *Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments*, in «Journal of Intellectual Disability Research» 45 (2001) 5, 371-383.

¹⁰ Cf. W.M.L. FINLAY – C. WALTON – C. ANTAKI, *Promoting choice and control in residential services for people with learning disabilities*, in «Disability & Society» 23 (2008) 4, 349-360.

¹¹ J. SPRAGUE – J. HAYES, *Self-determination and empowerment. A feminist standpoint analysis of talk about disability*, in «American Journal of Community Psychology» 28 (2000) 5, 671-695: 689-690.

¹² Cf. *Catechism of the Catholic Church*, LEV, Vatican City 21997, nn. 1776-1789.

wider group advocacy, in which the needs, rights, and preferences of a specific group are advocated for.

Gilmartin and Slevin explored the lived experiences of persons with intellectual disabilities belonging to a self-advocacy group. They found that group membership enhanced and promoted the personal development of participants, with individual and collective empowerment occurring for participants. In sharing about the experience of being in an advocacy group, one participant expressed how, «I think it's a good thing to speak up for yourself rather than people talking up for you»,¹³ and another how, «It has done a lot for us unless you speak up nobody will know what you are thinking».¹⁴

In their analysis of the effects of self-advocacy group membership on people with intellectual disabilities' social identity, Anderson and Bigby point to how self-advocacy is also an important way of furthering social inclusion.¹⁵

Mejias, Gill, and Shpigelman conducted interviews with members of a young women with disabilities empowerment support group.¹⁶ The participants had various disabilities, including mobility, intellectual, and visual. The researchers found that the women encountered various types of oppression, including environmental barriers, denigration of their bodies, and policies promoting exclusion. Besides internalization, such forms of oppression also prevented the women from developing a positive self-concept and a strong sense of belonging toward people around them. For many of the women the external negative messages contributed to negative self-perceptions. Participating in the group, however, helped increase the women's disability pride and self-confidence.

Self-confidence is the belief in one's abilities to accomplish a task or a goal.¹⁷ In regards to confidence increase as connected to self-advocacy group involvement, Fenn and Scior conducted a review of studies that examined both the psychological and the social impact of being a self-advocacy group member with intellectual disability.¹⁸ They found that increased confidence and empowerment were frequently reported outcomes. Confidence increase was particularly connected to aspects related to empowerment, like sharing perspectives and speaking to others.

Becoming an advocate for self and for others and learning what one can advocate for can help a person not only realize that they are protagonists of their own lives, but that they can also participate in the lives of others and making positive changes in them.

¹³ A. GILMARTIN – E. SLEVIN, *Being a member of a self-advocacy group. Experiences of intellectually disabled people*, in «British Journal of Learning Disabilities» 38 (2010) 3, 152-159: 156.

¹⁴ *Ibidem*.

¹⁵ Cf. S. ANDERSON – C. BIGBY, *Self-advocacy as a means to positive identities for people with intellectual disability: "We just help them, be them really"*, in «Journal of Applied Research in Intellectual Disabilities» 30 (2017) 1, 109-120.

¹⁶ Cf. N.J. MEJIAS – C.J. GILL – C.N. SHPIGELMAN, *Influence of a support group for young women with disabilities on sense of belonging*, in «Journal of Counseling Psychology» 61 (2014) 2, 208-220.

¹⁷ Cf. P. POTTER – A. PERRY, *Fundamentals of nursing*, Mosby, Inc., St. Louis, MO 2001.

¹⁸ Cf. K. FENN – K. SCIOR, *The psychological and social impact of self-advocacy group membership on people with intellectual disabilities. A literature review*, in «Journal of Applied Research in Intellectual Disabilities» 32 (2019) 6, 1349-1358.

I remember going to a disability advocacy conference together with people with and without intellectual disabilities in the United States. During the conference, there were different sessions in which people with disabilities could learn important advocacy issues and the ways of advocacy, while also expand their community network around issues of relevance to their lives. As support persons, we were there to help as needed and learn about important themes ourselves. People without disabilities can be allies and supporters of people with disabilities, journeying by their side and caring about the issues that make an impact in their lives.

Within the church, for example during the synodal process, ensuring that there are spaces in which people with disabilities can speak out (verbally or not) about their needs, wishes, and also about the contributions they'd like to share with the wider community, can make it clearer that they are welcomed and needed. At a wider disability advocacy level, too, when discussions and conversations around life issues happen, it is not up to family, friends, congregation members, and staff to take over the sharing. The letter should stem as much as possible from the direct experience of people with disabilities, and people close to them are to focus on that experience, supporting and helping as needed.

5. Developing a positive disability identity

Participation is connected to someone's contribution to their community, and of course to their individual life. Participation, however, is not just about doing, but also about being. Participation also includes the question of identity, of *who* is the person that participates. To address how a person views themselves and their identity, and how that influences their way of participating and contributing, can help provide a richer understanding of participation.

Disability has often been thought of in disempowering and negative terms. In more recent times, however, there has been a growth in awareness of how claiming a positive disability identity can be a meaningful and enriching journey. Gill specifically highlights four key phases that appear to be salient in the identity process: the first phase has to do with personal integration into society, the second one with personal integration with the disability community, the third one with internal integration of sameness and differences and forming group culture, and the last one with integrating how one feels with how one appears.¹⁹

Forber-Pratt and Zape analyzed disability identity development of ADA-generation college students with disabilities.²⁰ Through interview transcripts and observation notes synthesis, they developed as individuals with disabilities psychosocial identity development model, which is composed of four developmen-

¹⁹ Cf. C. GILL, *Four types of integration in disability identity development*, in «Journal of Vocational Rehabilitation» 9 (1997) 1, 39-46.

²⁰ Cf. A.J. FORBER-PRATT – M.P. ZAPE, *Disability Identity Development Model: Voices from the ADA-Generation*, in «Disability and Health Journal» 10 (2017) 2, 350-355. ADA being the acronym for the Americans with Disabilities Act, a major US civil rights law that affirms various protections for people with disabilities and that was signed into law in 1990.

tal statuses: acceptance, relationship, adoption, and engagement. Disability acceptance may occur on an individual scale, but also on the part of relatives, friends, and supporters. The relationship status is centered on the relational network with other people with disabilities that one creates. The adoption status is connected to the level in which individuals adopt disability culture values. The engagement status relates to becoming a role model for others and giving back to the disability community. Individuals, the authors point out, might be in more statuses at once and could have strong disability identity development without resonating with all statuses.

One element that comes up in both models presented is the concept of culture. After all, culture(s) influence and affect individuals from the beginning of their lives. For example, a person can identify and be influenced by national culture, religious culture, family culture, and political culture at once. They may also identify with disability culture.

Institute on Disability Culture co-founder Steven E. Brown wrote that,

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.²¹

Disability culture may be described as «a set of artifacts, beliefs, [and] expressions created by disabled people ourselves to describe our own life experiences».²²

Freire believed that there is a dual consciousness in people that are oppressed, that there is both an authentic being and an oppressor within them. In regards to the oppressor within, it is the process of internalization that causes the person who is oppressed to believe how they are seen by the oppressor, creating myths (or false images) that lead to a stance of dependence towards the oppressor's paternalism.²³

Developing a positive disability identity and letting go of external and internalized negative disability messaging, while also connecting to disability culture and its community rather than trying to fit in ableist narratives, can be transformative ways of growing in confident participation within the familial, educational, professional, spiritual, political and socio-cultural milieus that one inhabits.

Within the church, narratives around disability have often been disempowering. Nancy Eiseland writes that,

the persistent thread within the Christian tradition has been that disability denotes an unusual relationship with God and that the person with disabilities is

²¹ S.E. BROWN, *Movie stars and sensuous scars: Essays on the journey from disability shame to disability pride*, iUniverse, Lincoln, NE 2003, 80-81.

²² IDEM, *What is disability culture?*, in «Disability Studies Quarterly» 22 (2002) 2, 34-50: 50.

²³ Cf. P. FREIRE, *Pedagogy of the oppressed*, Continuum, New York 2001.

either divinely blessed or damned ... neither represents the ordinary lives and lived realities of most people with disabilities.²⁴

Elsewhere I have analyzed at more length pastoral history and practice pertaining to church and disability, but one element I would like to point to in this conversation is the example of sacramental access by people who have intellectual disabilities.²⁵ In the past, it was not uncommon for them to be denied eucharistic reception at Mass, as they were considered not able to understand or be aware of the difference between ordinary bread and wine and the eucharistic body and blood of Christ. What did this say about disability identity? Was there a strong paternalism and ableist attitude that basically “decided for” people with disabilities and treated them as not “worthy” as other human beings? In more recent times, sacramental access is (often) approached in a much more inclusive and accessible way. People with disabilities are also invited to be more involved in the various realms of the pastoral action of the church and of its faith life, even if the principles encouraged by ecclesial documents are not always energetically received and lived out in practical life.²⁶

6. Growing competence relationally

Each individual, whether with a disability or not, can positively contribute to society and to the church. Even if the feeling of positively contributing to others can help a person feel more confident in their capacities and skills, understanding their contribution and the competence it springs from solely on individual terms can be problematic.

McKenzie points to how an element of positively contributing, not merely understood as productivity, is learning how to live together. In this sense, a positive contribution to a community is not only an individual achievement, but a collective endeavor.²⁷ For example, if a person has an impairment, their competence in offering a specific contribution may not only be found within their individuality but also in the contexts that they inhabit, and whether these are enabling or disabling. In the interactive approach to competence McKenzie highlights, competence is the fruit of social interaction. Challenging static notions of impairment, she proposes a shift towards the notion of (poss)ability through which competence is not only located in the individual, but also in the extent to which a community is competent to deal with diversity and include all its members.

To support a person with an intellectual disability, develop their gifts and capacities, the role of community is very important. Gifts are for relationship, and

²⁴ N.L. EIESLAND, *The disabled God: Toward a liberatory theology of disability*, Abingdon Press, Nashville, TN 1994, 70-71.

²⁵ Cf. L. BADETTI, *Approaching disability: Pastoral history and practice analyzed through the models of the Church*, in «Concilium» 56 (2020) 5, 48-57.

²⁶ Cf. V. DONATELLO, *L'inclusione nei percorsi di educazione alla fede. Le indicazioni del Magistero ecclesiale*, in «Catechetica ed Educazione» 6 (2021) 1, 63-80.

²⁷ Cf. J.A. MCKENZIE, *Models of intellectual disability: Towards a perspective of (poss)ability*, in «Journal of Intellectual Disability Research» 57 (2013) 4, 370-379.

being able to call forth those gifts, support them in the process of development, and receive those gifts is as important as giving the gifts. Within the church, (poss)ability is a reminder of the ability the church community composed of people with and without disabilities has in creating new things and developing competence together, growing as a people and in confidence in one another.

7. Fostering belonging

In 2016, people with and without disabilities gathered in Rome to imagine together what a more inclusive and accessible church could be like. From this Living Fully conference, a charter was created to encourage a way forward, calling for a culture of belonging for all as something that should be ordinary.²⁸

In advocating for Christian communities as welcoming places where people with disabilities are valued and understood, a reality from which faith-based practice and teachings can be formed, Living Fully 2016 called for a theological reflection and praxis that is grounded in the participation and belonging of people with disabilities in their church communities.

Belonging deepens a very human aspect of inclusion. Belonging tells the person that they are valued and that they are missed if they are not present in community. This person-centered approach can help a person participate confidently in their community, with the sense that they are needed and wanted there, and that their contribution is important. In a similar way, people with disabilities can provide places of belonging for those in the church that do not identify as disabled. In a spirit of mutuality, belonging can be created by each person in a community, with or without disabilities, for others.

Conclusion

As participation is a major principle of Catholic social teaching, and people with disabilities are encouraged to participate in the synodal process, this article proposed some ways through which the participation of persons with disabilities can be encouraged and supported in individual and social life and in the life of the church. It did so by focusing on the development of self-determination skills, being in a self-advocacy group, claiming a positive disability identity, growing in competence relationally, and living out belonging.

²⁸ STATEMENT FROM LIVING FULLY 2016, *Disability, culture and faith: A celebration*, in «Cultures and faith» 24 (2016) 3, 208-219.

Vivere la partecipazione. Crescere in fiducia e appartenenza

► SOMMARIO

L'insegnamento sociale cattolico si impernia sul principio della partecipazione, invitando ogni membro della comunità di fede a partecipare ai processi sociali a favore del benessere sociale totale. Le persone con disabilità (PcD) non possono fare eccezione a questo invito a partecipare, soprattutto all'interno del processo sinodale promosso negli ultimi tempi. Questo articolo propone alcuni modi attraverso i quali la partecipazione delle PcD può essere incoraggiata e sostenuta nella vita individuale e sociale e nella vita della Chiesa. Questo viene fatto concentrandosi sullo sviluppo delle capacità di autodeterminazione, facendo parte di gruppi di autodifesa, rivendicando un'identità di disabilità positiva, crescendo in competenza relazionale e vivendo il senso di appartenenza.

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Advocacy; Autodeterminazione; Dottrina Sociale Cattolica; Empowerment; Identità; Persone con disabilità; Sinodalità.

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