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## Celebrating Life and Living Fully

### Statement from *Living Fully 2016: Disability, Culture and Faith – A Celebration*

#### Introduction

On June 23-26, in Rome, the Living Fully Symposium and Conference co-hosted by the Pontifical Council for Culture and The Kairos Forum, brought together persons with disabilities, theologians, clergy, religious, families, and laity for a four-day conference. We shared our stories, prayed together and explored the personal, pastoral and theological dimensions and implications of disability for people to live fully in the life of their congregations and communities. Our events identified the unique role and powerful witness that the Church can give in making ‘Living Fully’<sup>1</sup> possible for everyone. The presenters and delegates of the conference have developed the following statement that honors the reflections, discussions and themes that arose in the course of the four days. We hope it captures the expressions and voice of the hundred and sixty-five people, who travelled from thirteen countries across the world to participate.

*We believe that the Church plays a profound role in the ways that disability impacts and is impacted by all the cultures in which the Church lives and serves.*

#### Language

We recognise that language holds an important place in how the lives and stories of people are shared and discussed.<sup>2</sup> We will use the terms ‘**disabled persons**’ and ‘**persons with disabilities**’ throughout this document for specific meanings. We acknowledge that negative language and a lack of access ‘*disables*’ people, setting up physical, cultural, and attitudinal barriers, which prevent living fully. Within this document we will use the term ‘**disabled persons**’ to reflect this reality. However, people are first of all unique persons, worthy of God-given dignity. Disabling factors (physical, intellectual and/or emotional) may be a part of their lives, but “they are persons first.” Within this document we will also use the term, ‘**persons with disabilities**,’<sup>3</sup> to reflect this reality. Additionally, we wish to acknowledge that some persons with disabilities prefer the reference, ‘disabled persons.’

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<sup>1</sup> Gaventa, B. (23 June 2016) “Hidden in Plain Sight.”

<sup>2</sup> Reinders, J. (23 June 2016) Symposium introduction, “Seeing With the Eyes of God.”

<sup>3</sup> Masters, A. (23 June 2016) “Don’t Worry: He’s In A Perpetual State of Grace’ – Reclaiming A Catholic Tradition of Charity in Understanding Disability.” Symposium paper. The use of the plural of persons and disabilities in the reference, “persons with disabilities” is a theological reference that points to the uniqueness of each person, as well as the variability of the experience of disability. This is to counter the perception that individuals with disabilities share the same characteristics, concerns and experiences of disability.

Though their disability is not all of their identity, they feel it is a part of it, which is claimed with this reference.<sup>4</sup>

It is a constant challenge to reject limiting labels, stereotypes and assumptions. Therefore, we ask readers to examine their own opinions and language, which contribute to social isolation and diminished expectations, these can be more limiting than physical impairments and inaccessible environments. We call on everyone to build communities where all people are supported and valued.

## Context

Recent changes in thought and legislation across the world have thrown up significant challenges to traditional understandings of what disability means to the human person. The key issues identified for and by persons with disabilities are ones of rights, inclusion, and participation. The vision is one of full and active participation, by persons with disabilities and their families, in their communities and society. The key implication for the Church's culture and practice is that we could and *should* be the leader in that full and active participation, due to our understanding and promoting of the dignity of the human person. As the Body of Christ, the Church is called to move beyond issues of physical access and supportive care to an embodiment of the possibilities of "living fully" within both the Church and the culture in which it witnesses, evangelizes, and serves.

## The aims of the conference

Living Fully 2016 provided a creative space to reflect upon how the experience and expressions of people might provide 'new fields for evangelisation.'<sup>5</sup> The gathering enabled us to ponder both theologically and practically on 'the mystery of the world and in particular of the human person', with a particular focus on how we might provide a way to give 'expression to the transcendent dimensions of human life,'<sup>6</sup> where disability is present. The ever-growing field of Disability Theology provides an opportunity for all to encounter and explore the Gospel through the life experiences of persons with a disability, their families and loved ones. Living Fully 2016 initiated critical and hospitable conversations around the theological, pastoral and practical issues that are raised by the varied experiences of disability across contexts, faiths, and cultures. Together, people with and without disabilities

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<sup>4</sup> Long, S. (24 June 2016) "This is Me."

<sup>5</sup> Pontifical council for culture (1999) Towards a Pastoral Approach to Culture (TPAC)

[http://www.vatican.va/roman\\_curia/pontifical\\_councils/cultr/documents/rc\\_pc\\_pc-cultr\\_doc\\_03061999\\_pastoral\\_en.html](http://www.vatican.va/roman_curia/pontifical_councils/cultr/documents/rc_pc_pc-cultr_doc_03061999_pastoral_en.html)

<sup>6</sup> Ibid. Par. 1, citing Pope John Paul II in FN 1, *Discours à l'Assemblée Générale des Nations Unies*, 5 October 1995, n. 9; *Documentation Catholique*, XCII (1995) 920.

[http://www.vatican.va/roman\\_curia/pontifical\\_councils/cultr/documents/rc\\_pc\\_pc-cultr\\_doc\\_03061999\\_pastoral\\_en.html](http://www.vatican.va/roman_curia/pontifical_councils/cultr/documents/rc_pc_pc-cultr_doc_03061999_pastoral_en.html)

exchanged good practices, engaged in theological conversation, prayed, networked and celebrated the lives and faith of the delegates in all their diversity and giftedness.

## Living Fully 2016: Disability, Faith, Culture and Practice – A Celebration

*All Life is Gift: The rich diversity of the human story*

Every human being is ‘created in the image of God’.<sup>7</sup> In Christianity this is the essence of the gift of human life. The image of God is not a quality we earn but reflects the loving relationship that our heavenly creator maintains with each of us. Therefore, all human beings stand equal in their relationship with their Creator.<sup>8</sup> In Genesis God called the creation of human beings ‘very good’.<sup>9</sup> God rejoices in diversity. Pope Francis reminds us that diversity is not something to fear but that “differences are precisely our wealth”.<sup>10</sup> After all, “a world where everyone is the same would be a boring world”.<sup>11</sup> Celebrating diversity is indeed a ‘way to improve, to be more beautiful and richer’.<sup>12</sup>

Within this diverse human family created by and for God, every human being is precious (Psalm 139) and unique. As Cardinal Ravasi shared in his opening statement of the Living Fully symposium, “Every human being has both a physical aspect (*bios*<sup>13</sup>) and spiritual aspect (*zoe*).<sup>14</sup> These aspects make up the person’s ‘complex wholeness’.” In both of these different aspects ‘the human being belongs to God’s good creation and is holy’.<sup>15</sup> However, when persons with disabilities are met by others, they are often only recognised in their physical or intellectual aspect, thus *missing the person in his or her wholeness, missing the ‘wonder that is that unique human being’*.<sup>16</sup> There are other times when persons with disabilities have been romanticised as ‘God’s special angels’ who provide opportunities for ‘us’ to grow in grace through helping ‘them.’ This “contradicts our call to see Christ in all, and to be Christ to my neighbour.”<sup>17</sup> Further, it denies their humanity, setting the disabled persons apart from non-disabled persons, enhancing isolation and loneliness that is part of

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<sup>7</sup> Long, S (2016); Reinders, J. (2016)

<sup>8</sup> Reinders, J. (2016); Romero, M. (24 June 2016) “When We See Servulus: Learning How to Go On By Looking to the Past.”

<sup>9</sup> Braviner, B and Lucas, D (23 June 2016) “The Jesus Model: The Person with Disabilities and the Disabled God.”

<sup>10</sup> Pope Francis (11 June 2016) Address for the 25<sup>th</sup> Anniversary of the Concilio Episcopale Italiana (CEI), Disability Ministry; Sr. Veronica Donatello, Don Diego Pancaldo e Sr. Antonella Meneghetti (CEI) (23 June 2016) “O Tutti, O Nessuno.”

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> Cardinal Gianfranco Ravasi (23/6/16) *Opening address of Living Fully 2016 Academic symposium* 23 June 2016.

<sup>14</sup> Ibid.

<sup>15</sup> Matthews, P (24/6/16) “The Wonder of Who I Am.”

<sup>16</sup> Collectively reported in the papers and insights of all delegates, presenters and facilitators at LF2016.

<sup>17</sup> Masters, A (23/6/16).

being human.<sup>18</sup> All people are created in the image of God and as such, there is no ‘them and us but *only us*’.<sup>19</sup>

As proclaimed by the Psalmist in Psalm 139, all the delegates at Living Fully called for people to see every person as being ‘wonderfully made’.<sup>20</sup> Our lives are not valuable because of the state or condition of our bodies and minds. ‘All are equally loved by God, which means that there is no norm that renders the lives of some human beings more valuable than others.’

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As Pope Francis reminds us, ‘we must remove our sandals when we are on the holy ground’<sup>22</sup> of our encounter with another person’.<sup>23</sup>

### ***Persons living with disability within the Life, Mission and Culture of the Church***

Christians are called to celebrate the gift of life in the Church and are, together, the Body of Christ. As Christ’s body, we must therefore mirror the way in which he met people and offered belonging within the Kingdom of God. This sense of belonging was mirrored in the activities and vision of the Living Fully events, which included each and every person, no matter their presumed ability. When the Church forgets this and creates barriers for some to belong, ‘the Body of Christ is incomplete and does not reflect the whole image of God, it risks no longer being the Body of Christ’.<sup>24</sup> Persons with disabilities are among those who experience multiple kinds of barriers that exclude, both attitudinal and architectural. Disability is also often correlated with lack of opportunity to contribute to society, poverty, hunger and adequate housing. A common experience of the delegates suggested that their personal ‘call to apostolic and missionary capacity’ is often not recognised or facilitated. This can be due to a lack of knowing how to provide creative and ‘appropriate access’<sup>25</sup> for persons with disabilities in the life and mission of the Church. Pope Francis tells us, “There is widespread attention to disability in its physical, mental and sensory form”. He also notes that whilst there is an ever increasing welcoming attitude, ‘our communities are still struggling to practice true inclusion and full participation in a way that is ordinary’.<sup>26</sup> Living Fully 2016 recognised that when persons with disabilities and their families participate in

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<sup>18</sup> Based on LF 2016 papers: Long, S. (2016); Masters (23/6/16); Waldron, L. (24/6/16) “Issues of Disability, Loneliness and Isolation.”

<sup>19</sup> Gangemi, C. (24/6/16) quoting Canon. J O’Toole. (July 2014) Homily For Ongoing Formation Of Priests, Southwark.

<sup>20</sup> Matthews, P. (2016).

<sup>21</sup> Reinders, J. (2016).

<sup>22</sup> Pope Francis. (11/6/16).

<sup>23</sup> Matthews, P. (2016).

<sup>24</sup> Reinders, J. (2016).

<sup>25</sup> Dukes, Z. (25/6/16) “From Inclusion to Belonging: Navigating a Way Forward.”

<sup>26</sup> Romero, M. (2016) Pope Francis. (11/6/2016).

the Church, they are not usually present or welcomed from a culture of belonging and active participation for all, i.e., being part of the ordinary. Too often their participation is defined as something ‘special’, and thus by definition, still different.

At Living Fully 2016 the delegates felt that they were part of something where ‘Everybody’<sup>27</sup> was together, where each person felt that they were expressing, themselves and their faith, within a culture of equality and belonging.<sup>28</sup> The common experience that emerged from the conference was that the presence of each person and their unique contribution was valued as an ordinary way of being Church together, and the expectation was ‘that everybody had something to bring’.<sup>29</sup> Being part of a community that attends to the gifts of all, that listens, accepts and learns from each other was the common experience<sup>30</sup> of delegates. A Church where all people know their rightful place of belonging mirrors a culture of love and serves to ‘evangelise culture’ by loving and valuing God and every single person from within whom they are born to be (Mark 12:30-31<sup>31</sup>). “Our sacred spaces can and must become our safe places.”<sup>32</sup>

There are places where the Church lives out this call and vision in ways that profoundly impact its own congregations and the communities and culture in which they live. However, that is the exception, rather than the rule. Thus, the delegates of LF2016 have asked that we create a charter for the Church that all individuals, clergy and parishes can sign up to and use within their community, life and mission. We have created two: one that speaks more directly to the issues of theology and ecclesiology raised by the experience of disability, and a second that is in more inclusive language, reflecting the variety of voices and abilities present at this unique conference.

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<sup>27</sup> Gangemi, Tobanelli, Vincenzi, Swinton. (2010) The term ‘Everybody’ was developed by the research project “Everybody Has A Story: Meeting People with Intellectual Disability” and responding to their spiritual and religious needs (available from [cgangemi.kairos@gmail.com](mailto:cgangemi.kairos@gmail.com)).

<sup>28</sup> Gill, P. 2016 review document and Rae, E: “A Quest to Belong.”

<sup>29</sup> Henley, C. (2016) “Ask Not What the Church Can Offer.”

<sup>30</sup> FitzSimons, J. (2016), Conference A discussion.

<sup>31</sup> “‘Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength.’ The second is this: ‘Love your neighbour as yourself.’ There is no commandment greater than these.”

<sup>32</sup> Walsh. MB (23/6/16) “Autism, Culture, Church: From Disruption to Hope.”

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## The Living Fully 2016 Statement

### The way forward – Living an ordinary culture of belonging for all

This statement has emerged directly from the delegates of the Living Fully 2016 events and is directed to all of the world. The key recommendations highlighted in this statement are that:

We the Church, affirm the uniqueness, dignity, and value of each person as created in the Image of God. We recognise that disabled people have an important role to play within the people of God, but do not always feel their importance to God because of hard hearts, lack of imagination and misdirected pity toward them. They must, therefore, be welcomed and enabled to enjoy a place of belonging where their lives and gifts are recognised, valued, facilitated and celebrated. **In so doing, we, the Church, provide a profound contrast to cultures in which persons with disabilities and their families are too often neglected, isolated, excluded, and/or relegated to the margins of social and community life.**<sup>33</sup>

We, the Church, recognise and honour the expressions, experiences, insights wisdom and choices of persons with disabilities and their families, providing a model for culture, systems of care, social services and faith communities. The Church must learn from disabled people and their loved ones, and a space must be created to enable people to express their knowledge and faith in God. **In so doing we all become evangelists to others and to culture.**<sup>34</sup>

We, the Church, are willing to fully embrace the real experiences of persons with disabilities and their families, including the spiritual wounds that have been caused by neglect and/or exclusion from the Church itself. **In so doing we will live out our collective call to ‘be the living Body of Christ’,<sup>35</sup> reaching out to befriend, touch and welcome all in the Spirit of the living and risen Christ,** learning the stories and needs of others.<sup>36</sup>

We, the Church, recognise the joys and graces that come from a culture of belonging, where diversity is celebrated within the communal and faith filled life of the Church. **In so doing, we, the Church, will facilitate a cultural shift and witness to the full Body of Christ, which is enriched by all people who all, according to their way of being, enjoy access, belonging and contribution to the whole of that Body (1 Cor: 12). This will mirror the diversity of God’s creation and the strengths inherent in the human spirit.**

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<sup>33</sup> Demeter, D. (23/6/16) “Mental Obstacle Clearing.”

<sup>34</sup> Montali, M and Orso, L . (23/6/16) “MS Network: A Way Out of Isolation.”

<sup>35</sup> Bishop Paul Hendricks. (26/6/16) closing Address LF 2016.

<sup>36</sup> This was a common theme, highlighted in all papers and reflections of delegates.

We, the Church, affirm the gifts of every person and desire that disabled persons enjoy their right and opportunity to use these gifts in praise and service to God. Delegates of Living fully have asked that they are 'treated the same as everyone else'.<sup>37</sup> Living Fully repeats and agrees with the call of Pope Francis that our faith communities 'welcome everyone or no one'.<sup>38</sup> **In so doing, the people of God offer a prophetic witness to the world, reaching out to all people and offering a place where human, spiritual and legal<sup>39</sup> rights can be lived to the full.**<sup>40</sup>

We, the Church, honour the desire and capacity of persons with all forms of disability and their families to be in relationship with God, and to help lead others into prayer and worship. Disabled persons must be empowered to live out their personal call to discipleship and have important and valued roles within their faith communities. **In so doing, the worship and witness of the Church serves to call every single person to respond to the gift and mystery of life at the heart of the Church's teachings and sacraments.**<sup>41</sup>

We, the Church, recognise that attitudes, culture and practices in our faith communities and structures must change if we are to ensure a celebration of diversity.<sup>42</sup> Jesus himself spoke to this when he responded to the faith of friends who were willing to remove a roof for their friend to gain access to him (Mk 2: 1-12).<sup>43</sup> As in Pentecost, we remain open to all forms of communication and we are open to be evangelised through it, amazed and surprised by one another, our stories and common journey of faith.

**In so doing differentiated communication and symbolic language will be creative and ordinary ways to communicate and will contribute to the formation of culture, faith and liturgy.**<sup>44</sup>

We, the Church, ask that a culture of formation for clergy, religious and lay leaders and practitioners be developed and fostered that engages with prophetic insights<sup>45</sup> from the disciplines of disability and theology. **In so doing, a culture will be established in which welcoming the lives and faith of persons with disabilities is an ordinary way of forming the practice and teachings of faith communities and traditions.**<sup>46</sup>

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<sup>37</sup> Delegate. (26/6/16) "Creating a Charter for the Church."

<sup>38</sup> Pope Francis. (11/6/16).

<sup>39</sup> Legal rights here refer to responsibilities placed on the Church by disability legislation in certain countries.

<sup>40</sup> Reinders, J. (2016); Gaventa, B. (2016) and statement contribution.

<sup>41</sup> This was a collective message from all delegates and presenters at LF2016 events.

<sup>42</sup> Townsend, M. (26/6/16) Statement workshop.

<sup>43</sup> Masters, A. (25/6/16) Gathering Stories: "A Church Called to Love."

<sup>44</sup> Dukes, Z. (2016).

<sup>45</sup> Rooney, S and Grant, F. (24/6/16) "In From the Wilderness."

<sup>46</sup> Pope Francis. (11/6/16).

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**Additional insights were expressed by delegates who are creative learners and who have personally dealt with the multiple dimensions of disability:**

‘I have so much to offer; receive it.’

‘Treat me like you do everyone else.’

‘Being together is good and inspires people to act.’

‘I am valuable: Value me.’

‘Doing things together, with me not for me.’

‘Please be open to all forms of communication, be open to be evangelised through it, amazed and surprised by one another, our stories and common journey of faith.’<sup>47</sup>

‘It is a call to a culture of change, belonging and love.’

‘We can only live life to the full if we do it together, this is a model of community and mirrors what it means to be Church.’<sup>48</sup>

## **Conclusion**

The conference experienced what a ‘community of faith could look like,’ when persons with disabilities are valued and the community is confident that each person is ‘unique and unrepeatably, and any exclusion of any person would impoverish the community’.<sup>49</sup>

Living Fully advocates that Christian communities should be ‘homes’ where all who experience exclusion, isolation or disabilities, can feel understood, respected and valued.<sup>50</sup> As one delegate noted, the entranceway, the living room, and the dining space in a home, indicate growing degrees of welcome and hospitality. But at the heart of the home is the kitchen, where masks are lowered and love, presence and gifts are shared. We will make sure that all people are welcome within the ‘Kitchen of the Church’<sup>51</sup> where action and welcome is taking place, rather than being relegated to spaces in which the hospitality is less inclusive and real. This will happen when people are no longer disabled by lack of access and where together, the wisdom, gifts and insights of all people, of all abilities, guide and enrich the Body of Christ.

The Delegates of Living Fully enjoyed a common experience where they were able to make friends<sup>52</sup> where they felt united within a culture of joy and celebration, yet also one that challenged each participant to recognise the ways that our own attitudes and practices need

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<sup>47</sup> Mike Harris, specialist in symbolic and differentiated communication, summarizing discussions in Stream A.

<sup>48</sup> Julia FitzSimons, Stream A facilitator.

<sup>49</sup> Pope Francis. (11/6/16).

<sup>50</sup> Ibid.

<sup>51</sup> Ray, M. (26/6/16) Statement workshop.

<sup>52</sup> Vuk, M. (23/6/16). “Friendship with People with Disabilities – Ideal or Reality.”



to change and grow. From within this experience, we have also developed a charter for the Church that is inclusive of the voices and expressions of everyone at the conference with varying levels of understanding and communication. We advocate that its vision becomes an ordinary way of fostering a culture of celebration and belonging, calling all to build the Church in faith, hope, and love.”<sup>53</sup>

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<sup>53</sup> We acknowledge with thanks the contribution of the Livability charity in encouraging us to use aspects of their charter for change as a model and guide.

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## The Charter

### Living Fully within the Church

#### Because we are created in the Image of God, we will:

- ✚ Show unconditional love; do as Jesus did, valuing all people of all abilities.
- ✚ Each be the glue that joins people together to celebrate themselves and their creation, no matter their body form and way of communicating.
- ✚ Show that each of us is loved by God, and that we are each and everywhere in the presence of God. We will be a witness for Christ and follow him.
- ✚ Celebrate being a Eucharistic people by enabling all to truly live out his/her vocation.
- ✚ Be creative artists in the work of God and in response to God's call, helping all to see and treat one another as unique individuals, each as God's work of art, rather than by labels that limit and exclude.
- ✚ Ensure that people of all abilities and disabilities feel invited, welcomed, and received as full members of God's community.
- ✚ Commit to helping others find and experience their own innate sense of worth and belonging, because we bear the image of God, we are the Body of Christ and we are inspired by Holy Scripture and the life of Jesus.

#### Because we are called to love all people, we will:

- ✚ Love God, love others, treat and serve everyone the same.
- ✚ Lead by example, seek positive change and foster a culture of justice and belonging.
- ✚ Help people to find peace and feel welcome in the Church.
- ✚ Reach out by invitation and welcoming people from all over the world, especially people who have been disabled and excluded.
- ✚ Attend to, receive, listen and make time for persons with disabilities and their families to express their faith, needs, gifts, and call to discipleship.
- ✚ Be evangelisers of all abilities: to EveryBody and with EveryBody.
- ✚ Together, develop creative skills in communication and access. Our faith communities will be accessible to all and a place of belonging for all.

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**We believe that the Church where persons with disabilities are present is:**

- ✚ A place where creative ministry and friendship are an ordinary way of being together.
- ✚ A place where we 'Live Fully' within a culture of belonging.
- ✚ A community of love, joy, welcome and an invitation to reflect the image of God in the world.
- ✚ A space to share in faith and grow in friendship.
- ✚ A community where all people can respond to their call to be a disciple of Christ and enjoy ministering and evangelising with others.
- ✚ A community where each person can live out their innate uniqueness and rightful place in the world and community of faith.
- ✚ A community that sees beyond the labels and sees the person, not the disability or impairment.
- ✚ A witness to love at the heart of the Church.
- ✚ A community 'Living Fully' and giving witness to love in worship and service.

**Signatories**

All Delegates and Speakers at the Living Fully 2016 Events 23-26 June 2016

**Pontifical Council for Culture:** Cardinal Gianfranco Ravasi, Mons. Melchor Sánchez de Toca

**The Kairos Forum:** Bishop Paul Hendricks, Cristina Gangemi, Gill Chaddock

**LF2016 Team:** Hans Reinders, Bill Gaventa, Zachariah Duke, Anne Masters, Julia FitzSimons, Mike Harris