

## A Message on... People Living with Disabilities



Evangelical Lutheran Church in America  
God's work. Our hands.

### I. Introduction

As a church committed to the gospel of Jesus Christ, the Evangelical Lutheran Church in America (ELCA) is called to welcome all people in all its congregations and ministries into full participation as baptized members of the body of Christ (1 Corinthians 12:14-26). Christians confess that all members have been baptized into Christ and made part of his body. Just as in Christ “there is no longer Jew or Greek, there is no longer slave or free, there is no longer male and female” (Galatians 3:28), so also in Christ there are neither people with disabilities nor people without disabilities. All are one in Christ Jesus.

This church believes that God, as creator and sustainer, intends that society regard all people as of equal worth and make it possible for all—those without and those with disabilities—to participate freely and fully as members of society in all important aspects of common life.

God’s gift of unity in Christ and these convictions commit the ELCA to work toward the full, just and equitable involvement of people living with disabilities in its own life and in this society. This commitment has been expressed in the ELCA’s existing statements<sup>1</sup> and its various ministries. In recent years people who live with disabilities have achieved greater participation within this church and within society. In the latter half of the twentieth century the disability rights movement has secured many needed legal and civil rights.

Nevertheless, there is much more to attain in both church and society. There also are crucial reasons at this time for articulating better this church’s teaching, calling and commitments regarding ministry and mission with those who live with physical, sensory, intellectual, mental<sup>2</sup> and developmental disabilities.\*

These crucial reasons are many. The Lutheran communion around the globe has registered the need for closer attention to these concerns.<sup>3</sup> Actions by governments, employers and various other actors within the society of the United States continue to reflect inequality and resistance to equitable participation. The population of those with disabilities continues to face core issues of poverty, unemployment and underemployment. People with disabilities remain significantly underrepresented as United States citizens in all levels of the political process.

The positive trends toward in-home support have increased challenges around basic standards of care, quality of life and access to personal, social and economic services. The costs of

long-term care, rising national debt and an aging population have led to a political debate that increasingly expresses troubling signs. Political rhetoric increasingly expresses the belief that the economic cost of providing accessibility or other means for enabling participation in society for people with disabilities is too high or not worth the benefit to society.

Within the ELCA many believe and can testify from their own experience that this church’s ministry, life and work has fallen short of God’s call to provide means for ministry with and to people who live with disabilities. It is clear that this church can live into its identity as Christ’s body better than it has so far by increasing its attention to and more fully opening itself to people with disabilities. Its failures to do so scandalize Christ’s visible church and muffle its prophetic witness to society.

This message, therefore, provides an occasion for the ELCA to address concerns related to the participation of people with disabilities through theological reflection (Section II), confession (Section III), and calls to renewed commitment and action within the ELCA (Section IV) and in society at large (Section V).

### II. Perspectives of Christian Faith

#### Creation in the Image of God

God freely creates humankind in God’s image (Genesis 1:26-27), an image given clarity and promise in Jesus Christ (Colossians 1:15-20). Just as God freely creates and commits God’s self to human beings, so human beings reflect God’s image because they are creatures free to love and serve God, other people and the creation itself. Human freedom for such relationships constitutes the image of God<sup>4</sup> and is the ground of human dignity.<sup>5</sup>

While a person’s dignity is a gift of God, it is within individual relationships, families, communities and the larger society that human beings exercise that freedom. It is through participation in face-to-face relationships involving bodily actions, postures and mutual recognition that human freedom and dignity become apparent.<sup>6</sup> All people with disabilities are created in God’s image and share the gift of freedom for relationship and its dignity, regardless of their particular disabilities or range of personal capacities to respond to God and others.

The particular freedom of Christians is to live in the joyful assurance of a faith relationship with the God revealed in Jesus Christ, who loves all despite their sins. Theirs also is the freedom to live joyfully with and for their neighbor, regardless of any disabilities that either they or others may have.<sup>7</sup>

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\* A glossary is provided to help describe the meanings of these terms in this document.

## The Human Condition and Disabilities

Human beings are part of a world in which a variety of abilities and skills, impairments and disabilities<sup>8</sup> are a common feature of life.\* Vulnerability to and the risk of disability are a natural part of the human condition *for all people*. While most people may assume that they never will become impaired and disabled themselves, many individuals, in fact, will be impaired or disabled at some point in their lives.<sup>9</sup> For some, these impairments and disabilities will be temporary or moderate-term conditions, perhaps occurring near the end of life; for others, these will be either long-term or lifelong.

Human life emerges from within the natural world and is limited and conditioned by it. Physical, sensory, intellectual, mental and developmental disabilities arise within the natural and social worlds from factors that are genetic, chemical, behavioral, social and accidental. A number of disabilities appear to result from various combinations of these factors.

Whatever the causes, a disability or impairment requires a person to exercise his or her abilities and skills in ways affected by that reality. Only in rare cases is the disability so severe that it deprives or completely eliminates one's capacity to act. Even then there remains freedom for meaningful human relationships.

Medical cures and assistance are blessings, but cures are rare and, sometimes, not desired.<sup>10</sup> Like all aspects of health, living with a physical, intellectual or developmental disability is a fact of life, calling for the resourceful and determined exercise of one's other abilities and freedom for relationship.

All people are free to care for each other in ways that are appropriate, purposeful and meaningful to everyone involved. Flourishing relationships among people both with and without disabilities will be lived out in various mixtures of support, interdependence and dependence. Various forms can be mutually positive and can improve lives and social conditions.

## Sin and Injustice

In contrast to a Christian view of the human being as free in relationship, the most prevalent mindset within this culture—often present even within the church—champions individual autonomy or individual “independence.” This view equates “freedom” with being able to choose from among self-selected alternatives and with being in control of one's own life.

This mindset tends toward an idolatry of human will and often is connected with idealized human perfection. It substitutes unfettered autonomous human choice for human freedom in mutually responsible relationships. Instead of freely loving God and loving our neighbor as ourselves, this mindset celebrates using freedom for one's own wishes and toward one's own perfectibility.

This view of individual autonomy is false. The actions of *all* people require interdependence and are limited by natural causation, personal situation and location within a given social

context. This view, however, remains dominant, and our society tends to equate an idealized and unrealizable human perfection and autonomy with being “normal.” This view judges *all* people against this standard.

Against the standard of “individual autonomy,” people who have disabilities are judged as socially different from or even inferior to those who are “normal.” Because their capacity for individual autonomy may be compromised to some degree, they are regarded or treated as somehow less fully human than other people.

This standard contributes to the perception that people with disabilities are mainly objects in need of charitable care. Such perception leads many to disregard how people living with disabilities are worthy of respect and have the same basic rights as all members of society. Far too often being “handicapped” or “disabled” has been a limiting label and a motive for either a patronizing response or unfair treatment. The standard also has been used to justify inequalities in opportunities for employment and housing.

The standard of autonomy leads many to discount the fact that people living with disabilities also have wonderful capacities for relationships with others and significant abilities to contribute to society. The resulting judgments and labeling too often have prevented the joyous inclusion of the gifts, skills and personalities of many people with disabilities within families, churches and communities.

The emphasis on autonomy also has deprived people with disabilities of the freedom and responsibility to participate fully in making important life decisions for themselves and in experiencing the consequences of those decisions. It has deprived others of the experience and joy of knowing and working with them.

Whether intended or not, such attitudes and treatment demean and harm those who have disabilities and, in fact, impoverish the lives of all. These views and attitudes, actions and outcomes must be named for what they are—expressions of sin.

## Jesus Christ and Human Disabilities

The life, death, and resurrection of Jesus Christ—the Word that became flesh (John 1:14)—demonstrate that all aspects of life, including disabilities and impairment, are encompassed in God's loving care. In being born of Mary and living among us, Jesus took on all the risks and vulnerabilities of being human, including those of suffering hate, rejection, cruelty, injustice, disability and death. Jesus did not do so for the purpose of suffering these things for their own sake. Rather, his suffering was a necessary consequence of his walking the way of the cross (Luke 24:27) so that *all* might be reconciled to God (2 Corinthians 5:19).

Christians follow and pray to a living Lord who felt abandoned by God, suffered and died, all with hope in the promises of God. This crucified Lord no doubt experienced disability,<sup>11</sup> and the risen Christ's wounds were significant in his post-resurrection appearances to Thomas and the other disciples.

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\* See the glossary for the meanings of these terms.

They demonstrated that the same Jesus who was crucified, died and was buried (Apostles' Creed) in the flesh also was resurrected in the flesh (John 20:19-29). Death no longer has dominion over him, nor ultimate power or dominion over those who trust in his grace (Romans 5:16–6:11).

In his earthly ministry, Jesus' attitude was marked by compassion, understanding and a willingness to walk with all people, whatever their situations. He healed and cured people who were sick, impaired and disabled "because in him was the full presence of God."<sup>12</sup> He related to all around him in a way that acknowledged their full humanity. All believers who name Jesus as Lord are called to imitate his ways. Against this standard, it is clear that all have sinned and fall short of the glory of God (Romans 3:23).

Christians, then, understand the need to confess what we have done and what we have left undone that harms people living with disabilities. In light of sinful actions and God's call to love and justice, we acknowledge the need for confession as members of this church and society.

### **III. Confession**

When Christians examine themselves individually and corporately, they may be led to confess ways in which as individuals they:

- assume or act as if people with physical, sensory, mental, intellectual or developmental disabilities are fundamentally different or inferior rather than celebrate these individuals as sharing a basic humanity given in the image of God;
- too often assume that people's disabilities are the primary source of their identities rather than just conditions they live with;
- doubt the capability of people with disabilities to function competently in their own ministry settings in the positions to which God calls them in this church, whether rostered or non-rostered leaders; and
- assume an idealism of perfection that imposes a sense of being fundamentally different from and, often, superior to people with disabilities.

When Christians examine themselves individually and corporately, they may be led to confess ways in which congregations and other local ministries in this church:

- fail to prepare hearts and minds to welcome people with disabilities as sisters and brothers in Christ;
- fail to accept people living with disabilities as partners in a common ministry, although many are able to share their stories, invite others to faith in Christ, serve in the ministries of this church, and care for the needs of their neighbor in various ways;
- have fallen short of preparing church buildings to receive, welcome and ease the way for individuals with disabilities into their sanctuaries; and
- have not actively opposed—or have even encouraged—religious explanations that teach or imply that disabilities and impairments are punishments for

individual sins or for those of parents and other family members<sup>13</sup> or are sent as a test from God meant to bless, refine or redeem.<sup>14</sup>

When Christians examine themselves individually and corporately as part of this society, they may be led to confess ways in which:

- people without obvious disabilities are seen as self-controlled and autonomous, while people with noticeable disabilities, by contrast, are viewed largely as lacking in autonomy and personal responsibility, despite evidence to the contrary;
- the dominant mindset of this society idolizes the perfect body,<sup>15</sup> often based on images of perfection from the mass media;
- the practice of modern medicine too often exaggerates its ability to control natural processes,<sup>16</sup> regards people with disabilities primarily as those in need of a cure or as those who need to be fixed, and overlooks those who cannot be "cured";
- social structures have been prone to isolate people with disabilities on the margins or to hide them out of public view;
- political and social structures unduly and unjustly restrict the spheres of choice for people with disabilities and the degree of personal responsibility they are able to assume for themselves as participants and citizens in society; and
- many perceive universal access as a special accommodation and therefore not worth the effort or expense needed to change existing social structures, patterns of behavior or means of communication.

Such confessions are not ends in themselves. By the power of the God who creates all and who makes us alive in faith, such confessions become the occasions for all people to recommit themselves in freedom, hope, and joy to one another. They become the occasions for articulating the commitments and courses of action that could better conform this church to the ways of Jesus in the treatment of people living with disabilities. They become the occasions to seek justice and fuller participation in both church and society.

### **IV. The Church's Ministry and People with Disabilities**

This church commits itself to the full inclusion and equitable participation within its own life of all people along the entire spectrum of abilities and disabilities. The ELCA rejoices in the presence of individuals, congregations, ministries and organizations within it that have demonstrated this commitment in creative and sustained ways. We commend their work and witness and encourage their continued efforts.

At the same time, we acknowledge that this commitment belongs to every member of the ELCA and that the Holy Spirit is calling for new, renewed and continuing efforts that will please God and bless the neighbor in this respect. This church is called

to make fresh commitments in all dimensions of its ministry and mission among people with disabilities.

## Congregations

Congregations gathered around word and sacrament bear crucial responsibilities in the life of this church as centers for evangelical mission with doors open to all, including those living with physical, sensory, intellectual, mental and developmental disabilities. The goal is that all people, including those with disabilities, may participate fully in the assembly of God's people and may experience together being the body of Christ. Without the presence of people with disabilities, the visible church is less than the whole people of God.<sup>17</sup>

*The ELCA calls upon and encourages congregations to:*

- ensure that members or non-members who are disabled have accessibility to the worship space and transportation, with an appropriate companion, if desired;
- ensure that necessary alterations to worship practices are undertaken to enable participation, such as aids to interpretation of worship for people with visual and hearing impairments;<sup>18</sup>
- expect, encourage and support individuals with disabilities to assume leadership responsibilities in all aspects of congregational life, ministry and governance, with particular concern for worship leadership;
- plan for and include both children and adults with disabilities in the congregation's groups and all of its programs and outreach;
- undertake a periodic accessibility study of the congregation's facilities, programs and activities and make results of this audit available to all, such as on its Web site;<sup>19</sup>
- make specific plans to address the shortcomings revealed by an accessibility study and consult with people who have disabilities or their caregivers when planning and implementing physical improvements, programmatic innovations or schedule changes;
- welcome the leadership of individuals with disabilities as pastors, associates in ministry, diaconal ministers, deaconesses and lay staff;
- find appropriate ways to support caregivers of people who live with disabilities;
- support people with disabilities and caregivers during difficult decisions regarding level and location of care, independence and life milestones and to honor those decisions;
- develop relationships with Lutheran or other social ministry and community organizations that support people with disabilities so that opportunities and areas for cooperation, service and learning may be explored; and
- support advocacy by its members for public policies, programs and adequate funding to benefit the needs of people with disabilities and the common good.

*We commend:*

- congregations that audit and improve the accessibility of their facilities, programs and activities to people with disabilities; and
- congregations and synods that organize or host regular worship gatherings for people with disabilities and their families and friends when it is not feasible for them to participate in existing worship opportunities.

*We call upon rostered and lay leaders of congregations to:*

- be mindful of the circumstances and needs of people with disabilities and their caregivers for pastoral care and include in public worship, where appropriate, elements of lament with which the congregation can help them express their grief and frustrations as well as their praise, thanksgiving and rejoicing;<sup>20</sup> and
- identify and encourage people with disabilities who show potential to enter rostered leadership to consider such callings seriously.

*We urge individuals with disabilities to:*

- be clear and forthcoming about what they personally can and cannot do within congregational life and as potential leaders and to share their unique gifts and perspectives in their congregations and with the wider church;
- take initiative in exploring what accommodations in congregational life may be helpful, necessary and possible; and
- take initiative to develop systems of social support based on their individual needs.

## Synods

Synods and the ministries on their territories can play pivotal leadership roles in demonstrating commitment to people with disabilities and the value of encouraging their participation in its ministries. Synods also play a fundamental role in encouraging and supporting the development of rostered leaders who have disabilities.

*The ELCA commends and encourages synods that:*

- recognize the importance of ministry with people with disabilities and have given attention to foster such ministries;
- lift up congregations, outdoor ministries, campus ministries and other ministry sites that have made their facilities accessible to people with physical and sensory disabilities and included people with all kinds of disabilities in their ministry and programs; and
- have supported participation of youth with disabilities in synodical and churchwide<sup>21</sup> youth activities.

*We encourage synods, their congregations and other ministry sites on their territory to:*

- find appropriate ways to share their knowledge, experience and means with other congregations and ministry sites that wish to make facilities and activities more accessible and more inclusive of individuals with all kinds of disabilities; and

- support efforts to ensure accessibility and participation in ministries in their jurisdiction, such as campus ministries, outdoor ministries, Lutheran schools, chaplaincies and others.

*We also call upon synods, their bishops and bishops' assistants to:*

- help identify and encourage people with disabilities to attend seminary and enter rostered ministries;
- work closely with candidates with disabilities in order to receive their gifts for ministry and be willing to look carefully at their individual situations;
- work carefully and continuously with synodical candidacy and congregational call committees to help educate and sensitize their members to the gifts for ministry of people with disabilities and to the value of calling qualified people with disabilities to rostered leadership positions; and
- deliberately consider appointing people with disabilities, both rostered and lay, to their synodical candidacy and congregational call committees.

*We commend:*

- those synods, synodical staffs and call and candidacy committees that already have taken steps in these areas and encourage them to continue to do so.

*We urge people with disabilities who wish to attend seminary or who have studied for the ministry to:*

- be clear and forthcoming with synodical staff and candidacy committees and congregational call committees about what they can and cannot do in ministry settings; and
- take initiative to develop systems of social support based on their individual needs.<sup>22</sup>

## **The Churchwide Organization and Ministries**

In the ELCA people with disabilities and those who accompany them look to the churchwide organization for leadership, resource coordination and collaboration. For this reason, it is important for promises regarding financial resources and staff capacities to be realistic and clearly communicated as the churchwide organization seeks to fulfill its roles.

*The ELCA encourages the churchwide organization to:*

- strengthen efforts to publicize existing resources and provide support to synods, congregations, campus ministries, church-related educational institutions and communities of people with disabilities in the ELCA;
- make a professional accessibility audit of the churchwide organization's Web site and create a plan to implement changes in areas indicated by the audit;
- work with synods and Lutheran social ministry organizations to create, publicize and support online forums and conference call support groups for people with disabilities and their caregivers;
- find ways to connect those congregations and other ministry sites desiring to make physical, technological or communication improvements aimed at increasing

universal access to their facilities, programs and activities with relevant practical information and networks;

- encourage the production and distribution of worship, teaching and devotional materials in formats that enable full participation by those with disabilities;
- continue to increase the accessibility of the ELCA Churchwide Assembly and all other churchwide events for people with physical, sensory and other kinds of disabilities;
- continue to recognize and encourage networks and organized groups that support rostered leaders who have disabilities;
- work together with ELCA members, congregations, synods and affiliated organizations to advocate for public policies, programs and adequate funding to benefit the needs of people with disabilities and the common good; and
- make its policies and practices regarding ministry with and advocacy for people with disabilities substantially consistent with, whenever possible, those of its full communion partners and other ecumenical partners, both here and internationally.

*We commend:*

- the churchwide organization for its work to involve youth with disabilities through the Definitely Able Youth Leadership Event and in the Definitely Able Advisory Committee (DAC),<sup>23</sup> and we urge it to strengthen its work with youth with disabilities;
- the young leaders of DAC, and of the Lutheran Youth Organization for their spirited witness in and to this church regarding the involvement of young people with disabilities;
- the churchwide organization's work with the Lutheran Network on Mental Illness/Brain Disorders (LNMI);<sup>24</sup> and
- the project coordinators for Deaf Ministry and for Blind and Braille Ministry for their work on behalf of hearing-impaired and visually impaired people in the ELCA and the congregations and ministries which serve them.

## **Seminaries**

ELCA seminaries have a lasting influence in this church insofar as they seek to make their institutions more accessible and increase sensitivity about people with disabilities among their students, faculty and alumni. Their challenges include investing in improving the accessibility of their facilities for people with disabilities and giving attention to curricula and instructional resources that address ministry with people with disabilities. Such actions enhance the training for ministry of people with and without disabilities, equip future leaders and offer signs of hope for this church.

*The ELCA calls upon all of the ELCA's seminaries to continue to:*

- encourage and train students with disabilities for rostered and lay ministries in the church;
- periodically assess the physical accessibility of their campuses, the accessibility of instruction to students with visual and hearing impairments, and hospitality to and support of all students with disabilities;
- deliberately seek people with disabilities for appointments to their boards, faculties and staffs whenever appropriate;
- include attention in general instructional programs that help develop sensitivities to the long-term issues and needs faced by people with disabilities; and
- equip seminary students and congregations to reach out to people with disabilities and to lead congregations in becoming places of full participation.

### **Social Ministry Organizations**

Lutheran social ministry organizations have been in the forefront of this church in addressing the needs of people with disabilities and have a rich history and much experience with supporting people with disabilities, their families and caregivers.<sup>25</sup> Because of their distinctive work and experience, these organizations can provide critical initiatives and innovative models for this church.

*The ELCA calls upon Lutheran social ministry organizations to:*

- innovate effective ways to support people with disabilities who need their support and services to develop their abilities and to encourage them to participate in community life and society to the fullest extent possible;
- reach out to congregations, synods, Lutheran schools, seminaries, colleges, campus ministries and outdoor ministries in order to involve them in social ministry for people with disabilities and help them better understand the needs of people with disabilities and ways to improve their own accessibility and inclusion of people with disabilities;
- advocate for public policies, programs and adequate funding to benefit the needs and interests of people with disabilities and the common good; and
- encourage ministries and partnerships within The Lutheran World Federation to share with and learn from efforts around the globe to minister with and to people with disabilities.

*We commend social ministry organizations for their attention to:*

- finding the most effective means to support people living with disabilities and their families; and
- modeling collaboration with people with disabilities, their families and caregivers by providing carefully structured choice in all matters consistent with their abilities.

### **V. Society and People Living with Disabilities**

Society has a long history of mistreatment of people with disabilities, ranging from discriminatory to demeaning to even cruel.<sup>26</sup> While there are exceptions, attitudes, laws, and practices in the United States have unnecessarily and unjustly restricted the opportunities of many people with disabilities to act on their own behalf and to contribute to society.

This history began to change when people with disabilities and other concerned individuals began to speak out publicly on behalf of people with disabilities. This coincided with social service and social ministry organizations' efforts to improve the situations and care of people with disabilities. The greatest progress, however, has occurred when people with disabilities themselves formed the disability rights movement in the latter half of the twentieth century.

This movement and its supporters have worked to change attitudes and behavior by the passage of laws that have secured needed legal and civil rights. The goal has been to provide legal tools for people living with disabilities to exercise their rights. The goal has not been to seek "special" or "extra" rights, but to correct a long-standing history of denial of basic rights to people with differing abilities.<sup>27</sup>

Given the various social, economic and political challenges facing American society, there are credible reasons to be concerned that these systems of care and these legal gains might be in jeopardy for people with disabilities who need them.

The ELCA is aware that numerous issues need to be addressed in order to foster full inclusion and justice for people with disabilities. Toward that end it reaffirms these basic principles:

- all people have equal moral and legal status in this society, which includes a moral right to ethical treatment and inherent rights of self-determination and independence despite disabilities or impairment;
- all people deserve equal protection under the law. This protection includes equal access to public accommodations, facilities, programs and educational and economic opportunities. It includes protection from discrimination on the basis of ability/disability as well as protection from violence, intimidation and neglect at home, at school and in all other settings, public or private; and
- all people have a right to representation and participation in government and the exercise of citizenship, even when this requires reasonable forms of assistance for people with disabilities.

Further, the ELCA in its various ministries, organizations and expressions will:

- be guided by these principles in addressing those issues;
- call upon its members, in their service in the world, to partner with people with disabilities and other allies in pursuit of these principles; and
- stand with those who share these commitments and speak on behalf of those who are unable to speak for themselves.

## Employment and Poverty

The most typical way for people in the society of the United States to participate and contribute is through employment. Employment also provides structure to an individual's life, access to others without disabilities, and a way out of poverty. There are very few people with disabilities who cannot work, even though appropriate supports are necessary sometimes, and most desire to work.<sup>28</sup>

People with disabilities are much less likely to be employed than the general population, however, and are more likely to be under-employed. They are likely to earn less than others, and they and their households are more likely to live in poverty, especially if their disabilities are severe.<sup>29</sup>

The employment provisions of the Americans with Disabilities Act are necessary but not sufficient to counter these problems by increasing employment and economic opportunity.

*In light of these realities, the ELCA urges employers to:*

- think beyond entry- or low-level jobs for people with disabilities and to encourage appropriate career paths they might follow; and
- go beyond the requirements of the law in creative accommodations for otherwise qualified work, when necessary.

*This church calls upon federal and state governments to:*

- work intentionally with people with disabilities and especially those with severe disabilities to develop short- and long-term strategies to help low-income people with disabilities lift themselves out of poverty; and
- review and revise laws and regulations that may threaten benefits, living arrangements or places on waiting lists.

## Education

This church has a long tradition of supporting education for all. It has affirmed the importance of education for developing the innate gifts and abilities of people with disabilities by calling for qualified teachers, adaptive technology and other necessary provisions.<sup>30</sup> United States law has established the policy of educating children with disabilities, regardless of their disability or set of skills, in an individualized program of instruction in the least restrictive environment appropriate to their needs.<sup>31</sup>

*Toward the goal of providing education for all, the ELCA calls upon the federal government to:*

- maintain and strengthen the Individuals with Disabilities Education Act; and
- support appropriate funding for people with disabilities to receive higher education or technical training.

*We urge all colleges and universities, especially those affiliated with the ELCA, to:*

- be mindful of their opportunity and calling to serve the needs of people with disabilities and to recruit them actively and also provide appropriate services and financial assistance.

## Family Caregivers

A minority of people with disabilities need extensive individualized care-giving. Family members, especially women, tend to provide a significant portion of this care. These arrangements provide many benefits, such as maintaining mutually beneficial family relationships, but they also present extra challenges.

Some family members provide care in addition to their employment and other home responsibilities, while others forego employment and income in order to provide it. Caregivers who also are employed outside the home generally face significant challenges fulfilling responsibilities for both job and care-giving.

*This church encourages employers to:*

- accommodate the needs of employee caregivers with flexibility to the fullest extent possible; and
- refrain from penalizing employee caregivers by stigmatizing them or restricting their career paths.

The trend toward in-home services reflects not only a growing personal preference but also a more economical means for providing services. This commitment to increasing family support requires significant political will and a comprehensive redesign of service systems.

United States society is beginning to face these issues, but has not resolved them. While the Medicaid Home and Community-Based Services Waiver Program provides a way for states to meet their court-ordered responsibilities, spouses and minor children in this program usually cannot be paid as providers of eligible waiver services.<sup>32</sup> This exclusion often forces spouses or other family members to choose between providing care and earning an income.

*This church calls upon federal and state governments to:*

- increase funding for home and community-based care and eliminate waiting lists for it; and
- eliminate the exclusion of spouses from the Medicaid Home and Community-based Services Waiver Program.

## Providing Support and Staffing the Caring Professions

Both secular and faith-based social service agencies provide the support that many people with disabilities need. These agencies deal with immense complexity in providing and administering tailored support services for clients, often participating in a mix of public and private programs.

*The ELCA calls upon governments at all levels to:*

- adequately fund public programs for health and support services for those people with disabilities who depend on them and remain current in their payments to social services; and
- simplify complicated eligibility and funding processes that obstruct much-needed service and create unnecessary administrative expenses.

A staffing shortage is looming in the caregiving professions. This shortage can be attributed in part to social attitudes and injustice related to society's care for people with disabilities. It is tied, as well, to the public's low regard for many of these fields

and the relatively low pay for such work. Countering this shortage will require concerted and sustained efforts by government, schools, churches, businesses and non-profit organizations.

*This church challenges colleges and universities, technical and vocational schools, hospitals and social service agencies, especially its own affiliated institutions, to:*

- find and implement effective ways to attract, recruit and train people for service in these fields and work to retain them.

*We encourage congregations to:*

- lift up members who serve in these fields and invite them to share their experience with interested young people and others.

## **Disabled Veterans**

American servicemen and servicewomen who have disabilities resulting from military service deserve excellent care. However, the record of their care demonstrates an uneven quality and exposes a system riddled with problems. Resources available to the United States Department of Veterans Affairs for care have been limited. Effective care for post-traumatic stress disorder and mental illness can often be difficult to obtain.

Many believe that the bureaucratic fault lies in the adversarial nature of the current process for qualifying for benefits.<sup>33</sup> In addition, a variety of political, fiscal and budgetary pressures contribute to chronic underfunding. Reforms are needed to address these issues. This church commends all efforts to improve the timeliness, accuracy and consistency of decisions for benefits and the provision of accurate funding.

*The ELCA calls upon the appropriate branches or institutions of the federal government to:*

- assure that reforms and ongoing veterans' medical care are funded consistently and adequately; and
- assess and implement appropriate recommendations for reform in consultation with the Government Accountability Office and relevant congressional committees.<sup>34</sup>

## **Citizenship**

American citizens living with disabilities have a moral claim to exercise their political and legal rights, despite disparities that may exist in terms of capabilities, resources and knowledge. Forty-two states and three territories, however, bar at least some individuals with intellectual disabilities from voting, even when there is no cognitive impairment of a type that would make voting an unrealistic social goal.<sup>35</sup>

Such prohibitions reflect a false view of citizenship that assumes an idealized rationality; most people with disabilities, however, are quite capable of making reasoned political choices.<sup>36</sup> Not only do they understand their own desires and interests, but most also have a sense of the common good.

*This church calls upon all governmental jurisdictions to:*

- repeal prohibitions on the right to vote for people with disabilities, except when there are kinds and degrees of

mental impairments that would preclude voting as untenable.

## **VI. Conclusion**

When the word of God is preached and the sacraments are administered without the presence of all believers among us as the church, including people who are disabled, we are less than the whole people of God. We are less than we could be in the absence of their experiences, interests, skills and abilities to contribute to God's work of mission and ministry.

The Holy Spirit is calling this church to be mindful that those within it who live with disabilities are full companions in the journey of faith. A faithful response requires renewed efforts by all to live out together with joy and hope the freedom Christians have in Christ to love God and to serve the neighbor in secular callings.

In both church and society much remains to be done to ensure inclusion and justice for people with disabilities. Social and economic justice are not the sum total of what people with disabilities and their caregivers need, but they need justice as urgently as they need support, friendship and love. This church, through its members, various ministries, partners and organizations is being called to support this quest for justice and inclusion in both society and the church and to accompany those who seek it.

## Glossary of terms

The choice of language used regarding people in relation to their disabilities is both significant in itself, and a highly sensitive matter for many. While it may be generally agreed that terms with negative and offensive connotation or denotation should be avoided, there is no single set of terms recognized as universally “correct.” The lack of a “standard” lexicon is a consequence of many factors. These factors include the fact that all human language is in constant transition, and the preferences of different groups of concerned people from their experiences and insights about the meaning terms have been given. In general, the key terms regarding disability in this message can be read with the following background in mind.

### *Person or People with Disabilities*

The use of the terms *person* and *people with disabilities* represents preferred ways to refer to those who live with disabilities. This form puts emphasis on one’s personhood; it designates a person who happens to live with one or more disabilities. It also helps to avoid categorizations that readily are depersonalized, such as the “disabled” or “handicapped.”

### *Disability*

The use of the term *disability* describes a change in, a partial or complete loss of, or interference with one’s ability to perform a function or exercise a capacity that society considers typical of most individuals. People with disabilities seldom lack all ability to carry out most human activities. Rather, they often are differently abled or definitely abled. That is, they usually are able to accomplish the same activities in life as most others, if sometimes differently. Even when that is not the case, they have other abilities and gifts with which they live their lives and have relationships.

### *Impairment*

This term identifies the physical injury or condition that results in a disability. An impairment that results in some level of disability, however, does not mean that a person with this disability cannot do the activities that most people do. People with disabilities often have both capacities and creativity to do things in effective ways not typical for others. This is true even if doing the activity sometimes may take longer or require different efforts than it would for a majority of people.

### *Disabilities*

There are a number of broad categories of disabilities, each of which has its own characteristics. These characteristics often overlap, and individuals may have more than one kind of disability. What people with different kinds of disabilities have in common, however, is twofold. The first is the reality of living with a disability. The second is the experience of being treated differently. This experience often includes paternalism and discrimination—overt and covert—from other individuals and a range of social, economic and even religious practices.

*Although the variety of disabilities is broad, this message employs the following categories while recognizing there is considerable overlap and variation:*

### *Physical and Sensory Disabilities*

These terms indicate impairment of physical capacities that limit or destroy one’s ability to act and interact with others or to receive sensory stimuli from the environment. Sensory disabilities affect a person’s ability to see, hear, taste, touch or smell. Physical disabilities may affect, for instance, a person’s abilities to walk or handle physical objects and to use certain tools in ways most in society take for granted. They also may affect the capacity, for instance, to communicate with others, eat or breathe. People are known as visually impaired if they have a partial or total loss of their sight. People are referred to as having a hearing impairment if they have either a significant or total hearing loss.

### *Intellectual and Mental Disabilities*

These disabilities affect the capacity to process, express or interpret one’s own or other people’s ideas and messages. These may include sensations, emotions or social cues. For example, dyslexia rearranges written language in the brain and affects a person’s abilities to read and write. Clinical depression is a condition of the brain that can negatively affect a person’s moods, levels of energy, sense of self-worth and behavior.

### *Developmental Disabilities*

These disabilities result from sets of conditions that can adversely affect the development of children and youth and, in some cases, mature adults. The disabilities may be physical, intellectual, emotional, social or some combination of these. For example, Down syndrome causes delays in the ways children develop both physically and mentally. Autism (or Autism Spectrum Disorder) refers to a range of disorders in neurological development that give rise to various disabilities affecting behavior, communication and social interaction.

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## Endnotes

<sup>1</sup> See the ELCA social statements *Sufficient, Sustainable Livelihood for All* (1997), *Caring for Health: Our Shared Endeavor* (2003) and *Our Calling in Education* (2007) along with the document by Dr. Ronald Duty, “Actions Taken by the ELCA and its Predecessor Churches Regarding Persons with Disabilities and Disability Ministry” (2010). Links to all of these are available at [www.elca.org/disabilitiesmessage](http://www.elca.org/disabilitiesmessage) on the ELCA Web site.

<sup>2</sup> Whether *all* mental and intellectual illnesses or conditions should be considered disabilities is a matter of contemporary debate, although some clearly are. This message does not try to settle this matter, but accepts that at least some do give rise to disabilities and recognizes that much here may be taken in general to apply also to anyone with mental illness. A social message on mental health has been authorized by the ELCA Church Council (CC09.11.86c).

<sup>3</sup> One indicator of the worldwide concern about these issues is the adoption of Public Statement #13, “Advocacy for People with Disabilities.” at the Eleventh Assembly of the Lutheran World Federation meeting July 20-27, 2010, in Stuttgart, Germany. It recommitted the Federation to cooperate with the World Council of Churches and its Ecumenical Disabilities Advocates Network ([www.lwf-assembly.org/fileadmin/user\\_upload/Assembly\\_Outcomes/Consolidated\\_Report-Actions\\_Taken\\_by\\_Eleventh\\_Assembly.pdf](http://www.lwf-assembly.org/fileadmin/user_upload/Assembly_Outcomes/Consolidated_Report-Actions_Taken_by_Eleventh_Assembly.pdf), accessed 9/03/10).

<sup>4</sup> “Human freedom for God and for the other person and human freedom from the creature in dominion over it constitute the first human beings’ likeness to God.” Dietrich Bonhoeffer. *Creation and Fall: A Theological Exposition of Genesis 1-3*, tr. Douglas Stephen Bax, John W. De Grouchy, ed., in *Dietrich Bonhoeffer Works*, v. 3, Wayne Whitson Floyd Jr., gen. ed. (Minneapolis: Fortress, 1996), 67. See also where Bonhoeffer argues why the human likeness to God is not an “analogy of being” but an “analogy of relationship.” *Ibid.*, 65.

<sup>5</sup> The most well-known theological or philosophical explanations of the *imago dei* ground human dignity in the capacity for reason or the existence of a “rational soul.” See, for instance, Jean Porter, *Natural and Divine Law: Reclaiming the Tradition for Christian Ethics* (Grand Rapids: Eerdmans, 1999), 126-127. This raises the question, then, whether some individuals are left out since it seems to require, by definition, having “normal” human intellect, will and memory of events or information. Luther and the Lutheran Confessions do not depend on such views. Luther, in fact, objected to interpreting the image of God in terms of any powers of human beings and made no strong claims about it. He did insist that whatever it is, the image of God is “a unique work of God” and a work of the entire Trinity. Martin Luther. *Lectures on Genesis: Chapters 1-5*, Jaroslav Pelikan, ed. (St. Louis, Concordia, 1958), 57-64. Some relevant texts in *The Book of Concord* include Apostles’ Creed, Article I, of “The Small Catechism,” “The Formula of Concord, Solid Declaration,” I, 9-16; and “The Apology to the Augsburg Confession,” II, 15-22.

<sup>6</sup> Theologians have recently begun to reflect upon these dimensions of being human vis-à-vis the image of God. Mary McClintock Fulkerson emphasizes bodily interactions of people in relationship with God and in face-to-face recognition and interaction with one another in worship, fellowship and mutual service. See *Places of Redemption: Theology for a Worldly Church* (Oxford: Oxford University Press, 2007), see especially pp. 250-251. Hans Reinders stresses the relationship of friendship that God establishes and affirms in the Eucharist. See Hans J. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids: Eerdmans, 2008), 162, 337-347, 351, 365-366, 369, 374 and 376-377.

<sup>7</sup> *Sufficient, Sustainable Livelihood for All*, 3; and Luther, *On Christian Liberty*, tr. W. A. Lambert, rev. by Harold J. Grimm (Minneapolis: Fortress, 2003), 47-54.

<sup>8</sup> In the literature *an impairment* refers to a reduced or missing bodily or mental function that ordinarily a human being would be expected to have. A *disability* is any change, restriction or lack of ability to perform an activity in the manner considered typical for a human being, usually resulting from an impairment. See Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership*. The Tanner Lectures on Human Values (Cambridge: Belknap, 2006), 423-424, n. 5.

<sup>9</sup> At any one time, nearly one-fifth of the population of the United States has a disability. See Bureau of the Census, “Selected Disability Measures by Selected Age Groups: 2005,” [www.census.gov/hhes/www/disability/sipp/disable05.html](http://www.census.gov/hhes/www/disability/sipp/disable05.html) (accessed 3/27/2010). A person of the age of 20 has a 30 percent chance of becoming chronically disabled by age 65. See U.S. Social Security Administration, “Disability Benefits,” *Social Security Online*, [www.ssa.gov/pubs/10029.html#part2](http://www.ssa.gov/pubs/10029.html#part2) (accessed 4/19/2010). The percentage of people with disabilities *rises with age*. Nearly 52 percent of the population over age 65 report living with a disability; nearly 37 percent of them report that their disability is severe. Bureau of the Census, “Americans with Disabilities,” *Statistical Brief* (January, 1994), 1.

<sup>10</sup> This ambivalence has many sources. It may be the cost or complexity of treatment, for instance. Some in the hearing-impaired community, as another example, have rejected cochlear implants for personal use because of a strong identity with sign language and culture.

<sup>11</sup> A review of textual, historical and archaeological evidence about Roman practices of crucifixion in first-century Palestine has led medical and biblical scholars to accept that Jesus, like others who were crucified, experienced impairments to his wrists and nervous system that would be considered disabilities if he had survived or had experienced the same injuries in other circumstances. See William D. Edwards, Wesley J. Gabel and Floyd E. Hosmer, "On the Physical Death of Jesus Christ," *Journal of the American Medical Association*, 256:11 (March 21, 1986), 1460. Jesus' disablement during his trial and crucifixion has been identified and emphasized by Nancy L. Eiesland in *The Disabled God Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994). Because she is primarily concerned with physical disability, Eiesland draws certain theological and anthropological implications from the fact of Jesus' disablement that are not assumed here. For one criticism of Eiesland's views see Hans J. Reinders, *Receiving the Gift of Friendship*, 166-180. The crucial point is that Jesus shared the risk and the experience of human vulnerability to suffering, disability and death.

<sup>12</sup> ELCA, *Caring for Health*, 5.

<sup>13</sup> *Ibid.* The ELCA statement on health does not condone this view of the ultimate cause of illness. See page 3, for instance.

<sup>14</sup> Such messages either inappropriately blame the person who is disabled or give disabilities a meaning they do not actually have. Undoubtedly many experience God's blessings in the midst of living with disabilities, but that fact is a completely different matter than justifying disabilities by claiming that God inflicts them *in order to* bless, refine or redeem. See Helen Betenbaugh and Marjorie Proctor-Smith, "Disabling the Lie: Prayers of Truth and Transformation," in *Human Disability and the Service of God: Reassessing Religious Practice*, Nancy L. Eiesland and Don E. Sailiers, eds. (Nashville: Abingdon Press, 1998); see also "Disability and Meaning," in Arne Fritzon and Samuel Kabue, *Interpreting Disability: A Church of All and for All* (Geneva: WCC Publications, 2004), 10-11.

<sup>15</sup> Sharon V. Betcher, *Spirit and the Politics of Disablement* (Minneapolis: Fortress, 2007), 3, 5. Betcher also refers to this idolatry as our culture's "hallucination of wholeness."

<sup>16</sup> Gerald P. McKenny, *To Relieve the Human Condition: Bioethics, Technology, and the Body* (Albany: SUNY Press, 1997), 2, 18-19. Philip Hefner also argues that we tend to assume that "(1) Every possible technological advance should be brought to bear in health care ..., (2) every ailment should be prevented ..., (3) every ailment should be 'medicalized' ..., (4) Our bodies are high-performance sophisticated machines that should always function at their optimal level ..., [and] (5) our bodies are eminently fixable, and getting repairs when needed is a basic human right." Hefner, "Healthcare is about Bodies and Bodyselves," *Dialog*, 48:4 (Winter, December 2009), 309-310.

<sup>17</sup> See Stanley Hauerwas, "The Church and Mentally Handicapped Persons: A Continuing Challenge to the Imagination," in *Religion and Disability: Essays in Scripture, Theology and Ethics*, Bishop, ed. (Franklin, Wisconsin: Sheed & Ward, 1995), 59.

<sup>18</sup> This would entail, for instance, making available American Sign Language and Braille and large-print worship materials; it also may require attention to providing elements of the Eucharist for people with multiple chemical sensitivities.

<sup>19</sup> Instruments to help congregations do these things are available from the Congregational Accessibility Network, PO Box 959, Goshen, Ind. 46527-0959, Ph: 574-535-7053 or 877-214-9838, as well as on its Web site at: [www.accessibilitynetwork.net](http://www.accessibilitynetwork.net) (accessed 8/29/10). Other resources for various kinds of disability are also listed on this Web site.

<sup>20</sup> See Betenbaugh and Smith, "Disabling the Lie," 288-289.

<sup>21</sup> The ELCA Youth Gathering and the Definitely Abled Youth Leadership Event are illustrations.

<sup>22</sup> An example at the time of writing is the ELCA Disability Mentor Network.

<sup>23</sup> Information about the Definitely Abled Advisory Committee (DAC) and the Definitely Abled Youth Leadership Event (DAYLE) is available online at [www.elca.org/Growing-In-Faith/Ministry/Youth-Ministry.aspx](http://www.elca.org/Growing-In-Faith/Ministry/Youth-Ministry.aspx) (accessed 8/27/10).

<sup>24</sup> Information about the Lutheran Network on Mental Illness/Brain Disorders appears on the ELCA Web site at: [www.elca.org/Growing-In-Faith/Ministry/Disability-Ministries/Mental-Illness.aspx](http://www.elca.org/Growing-In-Faith/Ministry/Disability-Ministries/Mental-Illness.aspx) (accessed 8/30/10). It is a joint effort with The Lutheran Church—Missouri Synod to assist Lutheran congregations toward more effective responses to individuals with mental illnesses or brain disorders and their families.

<sup>25</sup> Lutheran social ministry organizations support people with disabilities with dedicated and experienced professional staffs and volunteers, innovative management and services, imagination and spirit in a challenging and changing social and fiscal environment. They also advocate for public policies, programs and funding that benefit people with disabilities with federal and state governments. At present, 18 social ministry organizations with service locations in 33 states, the District of Columbia, and the Virgin Islands are members of the Disability Network of Lutheran Services in America and support individuals with developmental disabilities. Several Lutheran hospital systems and other social ministry organizations also support people with rehabilitation services for physical disabilities, strokes and brain and spinal cord injuries.

<sup>26</sup> Parts of this history are told in Susan M. Schweik, *The Ugly Laws: Disability in Public*, (New York: New York University Press, 2009) and also in Eiesland, *The Disabled God*, 49-64.

<sup>27</sup> Key federal laws enacted are the Architectural Barriers Act of 1968, the Rehabilitation Act of 1973, the Developmental Disabilities Assistance and Bill of Rights Act of 1975, the Education for All Handicapped Children Act of 1975 (modified and expanded as the Individuals with Disabilities Education Act of 1997), and the Americans with Disabilities Act of 1990 (amended 2008). Court opinions in recent years also have accorded people with disabilities certain rights because of their differing abilities. In the literature, it has been argued that there is historical correlation between the passage of disability rights legislation and the repeal of municipal laws designed to control the public appearance and public behavior of people with disabilities. The last known such law was repealed by the City of Chicago in 1972. See Schweik, *The Ugly Laws*, 280-281.

<sup>28</sup> U.S. Census Bureau, Distribution of Selected Characteristics of Individuals 25 Years and Older by Disability Status: 2005, [www.census.gov/hhes/www/disability/sipp/disable05.html](http://www.census.gov/hhes/www/disability/sipp/disable05.html) (accessed 3/22/10). About one-third of working people with disabilities are limited in the kind of work they can do.

<sup>29</sup> *Ibid.* In 2005, for example, the poverty rate for people whose disabilities were not severe was 25 percent higher than for people who were not disabled, and the poverty rate of people with severe disabilities was three times that of people without disabilities.

<sup>30</sup> Evangelical Lutheran Church in America, *Our Calling in Education*, (Chicago: ELCA, 2007), 26.

<sup>31</sup> Nussbaum, *Frontiers*, 205, 207-208. Nussbaum notes the importance of the court's opinion in deciding the case of *Timothy W. v. Rochester New Hampshire School District* 875 F. 2nd 954 (1st Cir. 1989) cert. denied 493 U.S. 983 (1989). See also *Our Calling in Education*, 30, 34, 46-47 for the ELCA's position on these issues.

<sup>32</sup> "Medicaid Home and Community-based Services (HCBS) Waivers: Overview," Workworld, Employment Support Institute, School of Business, Virginia Commonwealth University, [www.workworld.org/wwwwebhelp/medicaid\\_home\\_and\\_community\\_based\\_services\\_hcbs\\_waivers\\_overview.htm](http://www.workworld.org/wwwwebhelp/medicaid_home_and_community_based_services_hcbs_waivers_overview.htm), (Accessed 5/6/10).

<sup>33</sup> In the current system, the burden of proof falls on the veteran to prove the legitimacy of a claim while the defined role of the United States Department of Veterans Affairs is to determine that all claims are not fraudulent before those claims are approved. Linda Bilmes, "Soldiers Returning from Iraq and Afghanistan: The Long-term Costs of Providing Veterans Medical Care and Disability Benefits," *Faculty Research Working Paper Series*, RWP07-001, (Cambridge, Mass: Kennedy School of Government, Harvard University, January, 2007), 7, found at: <http://web.hks.harvard.edu/publications/workingpapers/citation.aspx?PubId=4329>, 12 (accessed 4/27/10).

<sup>34</sup> Recommendations have been made by a variety of organizations and commissions. One important example comes from the Veterans' Disability Benefits Commission of the United States Congress (see Eric Christensen et al in *Final Report for the Veterans' Disability Benefits Commission: Compensation, Survey Results, and Selected Topics*, prepared for the Veterans' Disability Benefits Commission by C.N.A. Corporation, Alexandria, Va., 2007 available at [https://www.1888932-2946.ws/vetscommission/e-documentmanager/gallery/Documents/Reference\\_Materials/CNA\\_FinalReport\\_August2007.pdf](https://www.1888932-2946.ws/vetscommission/e-documentmanager/gallery/Documents/Reference_Materials/CNA_FinalReport_August2007.pdf), p. 13 [Accessed, 4/27/10]). A second important example comes from the President's Commission on Care for America's Returning Wounded Warriors (see "Serve, Support, Simplify: Report of the President's Commission on Care for America's Returning Wounded Warriors," Washington: 2007) [www.veteransforamerica.org/wp-content/uploads/2008/12/presidents-commission-on-care-for-americas-returning-wounded-warriors-report-july-2007.pdf](http://www.veteransforamerica.org/wp-content/uploads/2008/12/presidents-commission-on-care-for-americas-returning-wounded-warriors-report-july-2007.pdf) [accessed 4/27/10]). Other recommendations by the Government Accountability Office are online at [www.gao.gov/docsearch/featured/disability\\_benefits.html](http://www.gao.gov/docsearch/featured/disability_benefits.html) on the GAO Web site.

<sup>35</sup> Nussbaum, *Frontiers*. 195.

<sup>36</sup> *Ibid.*, 98. For important research about voter choice and discussions of voter rationality that support this point, see Angus Campbell, Philip E. Converse, Warren E. Miller and Donald E. Stokes, *The American Voter* (New York: Wiley, 1960; reprint, Chicago: U of Chicago, 1976) and Sidney Verba and Norman H. Nie, "The Rationality of Political Activity: A Reconsideration," in *Controversies in American Voting Behavior*, Richard G. Niemi and Herbert F. Weisberg, eds. (San Francisco: W. H. Freeman and Co., 1976), 46-47.