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Chapter Bulletin

Number 8

TO: All Chapters

FROM: Issues and Positions Committee

DATE: July 13, 2017

RE: ***Proposed New Position Statement on Aid in Dying and Review of 3 Existing Positons***

In preparation for the 2017 annual Fall Board of Governors meeting, the Issues and Positions Committee requests the review of the newly drafted position, **Aid in Dying**, and three existing positions including:

- Assistive Technology
- Direct Support Professionals
- Family Support

The Committee will review and, where needed, incorporate comments and suggestions. The amended positions will be presented at the Board of Governors meeting in October.

You may access all four positions by clicking here: [2017 Positions Under Review](#)

Please return any recommended changes to MaryBeth Schneider via e-mail (schneiderm@nysarc.org) or to the State Office via mail no later than August 18, 2017.

All NYSARC Positions Statements can always be found on our website under the About Us tab. [Click here](#) to view the complete document.

If you have any questions or would like a hard copy of the positons, contact MaryBeth Schneider at the State Office. We look forward to your input. Thank you.

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ASSISTIVE TECHNOLOGY

Assistive technology refers to external devices that are used by children and adults with intellectual and other developmental disabilities to enhance and increase independence, mobility, communication, environmental control and choice. Assistive technology helps the individual with daily life functions and facilitates inclusion in the community. Assistive technology also includes direct services and training that assists the individuals with selecting, acquiring or using such devices.

It is NYSARC's position that:

- **Assistive technology must be readily available and affordable throughout the life span of individuals with intellectual and other developmental disabilities.**
- **Technological innovators, designers and manufacturers must be educated to the needs of individuals with intellectual and other developmental disabilities to ensure the design and development of useful products.**
- **People with intellectual and other developmental disabilities, their families and support professionals must be educated about the benefits of assistive technology.**
- **Individuals knowledgeable about people with intellectual and other developmental disabilities and familiar with current technology must be involved in assessing the needs of the person to ensure the selection of appropriate devices.**
- **Professionals in the field must be well informed of funding and resources for assistive technology. It is essential that information and assistance in how to acquire assistive technology be provided to persons with intellectual and other developmental disabilities and their families.**

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly

DIRECT SUPPORT PROFESSIONALS

A stable workforce of caring, competent, creative, well compensated, and qualified Direct Support Professionals is essential to providing safe, high quality and effective supports and services for people with intellectual and other developmental disabilities.

It is NYSARC's position that:

- Direct Support Professionals must receive wages and benefits sufficient to attract and retain the workforce to fully support people with intellectual and other developmental disabilities living in the community.
- Relevant funding sources must support provider agencies in delivering high quality, certificate based training which covers the essential knowledge, ethical principles and practices, and skills necessary for effective direct care support.
- Training must ensure that Direct Support Professionals be educated in the philosophy and values that persons with intellectual and other developmental disabilities are members of the community and should have every opportunity for choice and control over their lives.
- Providers must foster the professional and personal development of Direct Support Professionals by providing access to continuing education and training.
- National, state and local private and public entities must engage in policy initiatives that facilitate employment placement and offer financial supports as needed to increase the number of people employed in direct support work.
- Staff assignments of Direct Support Professionals must be thoroughly evaluated in order to minimize unnecessary transfers and prevent the resulting disruption of the continuity of service to persons with intellectual and other developmental disabilities.
- A work environment must be provided that will foster optimum employee satisfaction.

Adopted October 25, 2003 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly

FAMILY SUPPORT

NYSARC believes that the ability of families to attain a normal lifestyle for themselves and their family member with intellectual and other developmental disabilities should be maintained and continually strengthened. Their unmet needs should be addressed on every level in whatever way that is most effective.

- **It is NYSARC's position that:**
- **The family is usually the best source of support for an individual with intellectual and other developmental disabilities.**
- **Family opinions, concerns and interest must always be listened to and be considered priority in service planning and in every facet of the individual's life.**
- **In addition to family, other supports and services must be available throughout the life of this individual.**
- **The support necessary for the individual should be determined by the individual and the family.**
- **Families must be provided with sufficient information to make informed decisions and to advocate for services that will best meet the needs of for their family member.**
- **These supports must assist families in the promotion of inclusion of children and adults with intellectual and other developmental disabilities in every aspect of their life in the community.**
- **There must be a community based support network of interested citizens and family members as part of the community that helps facilitate access to community resources.**
- **Advocates for local, state and national policy must be family centered and reflect the principles and goals of person-centered and self-determination strategies in all of their advocacy efforts.**

Adopted October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly

MEDICAL AID IN DYING- Draft

Individuals with intellectual and developmental disabilities are first and foremost citizens and as such are entitled to all of the fundamental rights, both explicit and implied, that are guaranteed to, and enjoyed by all people under federal and state laws. Therefore, NYSARC asserts that any rights included in any laws legalizing medical aid in dying should be guaranteed to people with intellectual and developmental disabilities.

It is NYSARC's position that:

- Mentally competent adults capable of making decisions for themselves who are dying of a terminal illness (typically 6 months or less to live) should have the option to obtain a prescription from their physician for medication if end-of-life suffering becomes unbearable so they can bring about a peaceful death.
- Additional protections must be in place for individuals with intellectual and developmental disabilities beyond requiring two physicians to sign off and a mental health referral if mental capacity is in doubt.
- Prior to providing a prescription medication, physicians should be required to confirm that terminally ill, mentally competent adults are fully informed about all end-of-life options including comfort care, hospice care, pain control, and medical aid in dying.
- Giving mentally competent, terminally ill adults the choice to end their own life is the same as allowing competent, terminally ill adults the choice to decline other treatments, like CPR, intubation, and artificial nutrition.
- The wishes of mentally competent adults who have clearly and competently expressed them should be honored by caregivers and health care providers.
- All persons with intellectual and developmental disabilities are valuable and deserve respect consistent with human dignity throughout their life. The value of a person's life is not related to the type, degree, or severity of disability.
- The personal autonomy, liberty, freedom, and dignity of each individual with intellectual and developmental disabilities must be respected and supported.