



Speaking out for people with intellectual and developmental disabilities



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## Reminders: Help VOR Grow!

**Challenge!  
Recruit 5 New  
VOR Members  
Today!**

**Celebrating  
Home: Holiday  
Shop and  
Benefit VOR**

**Make a Lasting  
Impact with a  
Will Bequest**

# VOR Weekly News Update

*News and views for VOR Advocates*

Notice: A *VOR Weekly Update* will not be published on Friday, November 23, 2012. Happy Thanksgiving!

**Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider [joining VOR](#) and receive this E-News Update publication weekly!**

**VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities**

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7. Final Results of the National "Natural Support" Survey

***Quotable, by Saskia Davis***

## VOR and You

1. Happy Thanksgiving

"We tend to forget that happiness doesn't come as a result of getting something we don't have, but rather of recognizing and appreciating what we do have."  
(Frederick Keonig)

In this Thanksgiving Season, all of us at VOR are

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counting our blessings and expressing gratitude for our collective strength to carry out our shared mission on behalf of people with intellectual and developmental disabilities.

THANK YOU to all VOR members for your consistent generosity in time and resources to ensure that VOR is as strong as we need to be for years to come.

Happy Thanksgiving!

## **2. Remember VOR on shopping's "Black Friday"**

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If your holiday shopping begins the day after Thanksgiving, find gifts for family members, teachers, co-workers, and friends at [Celebrating Home. 50% of your purchase will be donated to VOR.](#) This is an easy no crowd, no midnight shopping, no "door busting" opportunity to get some of your holiday shopping taken care of in the comfort of your own home, while benefiting VOR at the same time!

For those individuals on your gift giving list that have everything and need nothing, consider honoring them with a donation ([online](#) or [by mail](#)) to VOR in their honor, or giving them the gift of a VOR membership ([online](#) or [by mail](#)). Thank You!

## **Reaching the Media**

### **3. The truth about what has happened at Jacksonville Developmental Center**

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***The State Journal-Register (Illinois) \* November 9, 2012 \* Commentary by Lonnie Johns, Chairman of the Committee to Protect the Residents of JDC***  
**Excerpts**

When it comes to closing Jacksonville Developmental Center, advocates and state bureaucrats have shown little regard for the whole truth.

An advocate claims that when Lincoln and Howe closed, the "great majority of their residents" were "successfully transitioned into group homes." No. more than 75 percent of their

residents were moved to other State Operated Developmental Centers (SODC).

Claims are made that a U.S. Supreme Court decision, [\*Olmstead\*](#), requires JDC to close. But advocates never directly quote from *Olmstead* because the court decision requires that people have more choices, not fewer choices, and *Olmstead* doesn't require the closure of anything.

What has actually happened at JDC?

Kevin Casey [Director of Illinois' Division of Developmental Disabilities] sent letters, via certified mail, to parents and guardians giving them four days to agree to have their resident of JDC evaluated by Community Resource Associates (CRA) or the state would move that resident to another placement without receiving the permission of the parent or guardian.

The State pays CRA \$150,000 a month plus \$5,300 for each resident they evaluate, although the best and most comprehensive evaluations are done by those who actually know the resident of JDC, the staff of JDC.

Residents who have left JDC have been arrested, injured, run away from their group homes and been confined to their rooms.

Casey claims that JDC costs \$200,000 per resident, and group homes \$84,000. The real JDC figure for 200 residents is \$127,629 per resident, and with 181 residents it is \$141,026.

Group homes providing the same level of care as JDC will cost from \$148,000 to more than \$200,000 as it is much more expensive per resident to provide 24-hour registered nurses, behavior therapy, etc. at a small group home.

As they testified on Oct. 30, parents and guardians have been threatened, ignored, misled, prohibited from visiting other SODCs, and told by CRA employees that CRA will help them only if they agree to place their JDC resident in a community group home.

On Sept. 14, the State sent a letter to all Illinois group homes offering an incentive if only they would take at least eight residents of JDC: up to \$60,000 for remodeling, double the amount of up-front money, a new \$200 a month for utilities, advance payments every 3 months, and paying all state money due the group home before paying others owed state money.

This is what “person-centered” planning has come to be under the leadership of Casey and Governor Quinn.

### [The Growing Burden on Caregivers: A Focus on Natural Supports](#)

#### **4. Natural Supports Defined**

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##### **UC Davis Extension \* Center for Human Services**

Natural supports are individuals and resources a family can access “naturally”, independent from formal services.

#### **3. VOR's View**

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Natural supports are typically free caregiving provide by a disabled person’s immediate family, and sometimes extended family and friends.

In this difficult economy, policymakers are quite tempted to support and expand free natural supports. Some advocates leverage this temptation and oversell the virtues of natural supports while also seeking closure of specialized residential (large and small), supported employment, and other services: “Supporting families is the pathway to a sustainable system and a sustainable future” (*Nancy Thaler, Executive Director, NASDDDS; see article below*).

However, how “natural” is it for a middle aged person to be living with, and supported by, elderly parents? There are an unprecedented number of families in exactly that situation, arauably due to adagressive efforts over the

years to dismantle specialized services and unreasonable pressure by advocates and states on families to take on caregiving ("natural support") duties in the family home.

In 1997, author Fern Kupfer, translated the motives behind lawmakers' support for "natural supports" this way:

*"I said it 15 years ago, but it needs saying again: the view that the 'home' is the best place for every child has dangerous ramifications. Government funds are cut for human services under the guise of anti-institutionalization. Well-meaning reformers who tell us how terrible institutions are should be wary lest they become unwilling accomplices to politicians who only want to walk a tight fiscal line. It takes a lot of money to run residential facilities. No politician is going to say he is against caring for the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, 'You got your troubles, I got mine.'" ("My Turn: Home Is Not For Everyone – Placing a special-needs child in an 'institution' does not mean that you are a bad mother," *Newsweek*, December 8, 1997).*

Some advocates will "talk the talk" and acknowledge that choice for service options, including natural supports, must be part of the equation, yet many of these same advocates promote deinstitutionalization and the continued dilution of specialized care options. For example, the Arc of Indiana, calling for a "cultural change," said this about natural supports in its "Blueprint for Change" (Fall 2011):

"Major policy shifts must be made to make the development of Natural Supports part of people's lives—making natural supports and not just system supports the option families see, while recognizing employment and natural supports are not enough for

some and that an efficient, responsive and flexible system of paid supports will always be needed and utilized to provide the support people need—especially as life changes.” ([Blueprint for Change](#), Indiana ARC, quoting the “Big Minds Group”).

The Big Minds Group, a “national leaders in the field of developmental disabilities,” was convened by The Arc of Indiana to assist in the development of the Arc’s “Blueprint for Change.” Most members of the [Big Minds Group \(p.4\)](#) champion deinstitutionalization and The Arc of Indiana itself boasts that Indiana is the “largest state without state institutions for people with developmental disabilities.” A 2010, the [Associated Press article](#) reported that some Indianans with disabilities were being referred to homeless shelters for day services; more than 10,000 were waiting for services. In 2011, an Indiana Arc [task force report](#) found that the waiting list had grown to over 19,000 people, some who waited more than 12 years. The dearth of specialized services in Indiana created this crisis, one that the Indiana Arc expects to be addressed, in part, by family caregivers.

In any state, an increased willingness by families to embrace “natural supports” will immediately reduce those waiting for services, but is that really a solution or just better numbers on paper? According to Denver Fox, Ed.D, whose organization surveyed 500 families about their "viewpoints, attitudes, successes, and concerns" about the topic of "natural supports":

*“[N]atural supports’ has become more prominent in discussions regarding providing services for individuals with disabilities - especially in the presence of long - and perhaps never-ending - waitlists for services, particularly for individuals with intellectual and developmental disabilities. Some have posited that “natural supports” should fill in the gaps. or*

*perhaps even take the place of, paid services for individuals with disabilities." ([Final Results of the National "Natural Support" Survey, April 2011](#) (see also, [article below](#))).*

In conclusion, if a family has access to adequate natural supports and chooses this arrangement over specialized supports, VOR supports it. However, consistent with our mission in support of high quality care and human rights for all people with intellectual and developmental disabilities, natural supports should not be imposed on families when doing so creates an impossible burden on too few people to the detriment the individual's and the family's mental, physical and financial health, and indeed, risks separating the family unit itself.

#### **4. NASDDDS' View: Supporting Individuals Living with Families is the Foundation of a Sustainable Future; Two States'(CT and MO) Efforts to Strengthen their Support of Families**

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**[Community Services Reporter](#) \* August 2012 \* by Nancy Thaler, Director, National Association of State Directors of Developmental Disabilities Services (NASDDDS)**

##### ***Excerpts***

Today close to 60 percent of people with intellectual/developmental disabilities (I/DD) receiving services live in their families' home ([National Residential Information Systems Project RISP 2010](#)) which means that families are primary support for the majority of people enrolled in services. This percentage of people getting supports in their home has been growing as states have responded to family preferences for in-home supports and as they look for alternatives [to] too expensive and hard to staff 24-hour residential arrangements – group homes.

Waiting lists continue to grow and we know that the extraordinary funding increases of the past two decades are not likely to continue in the future. States have already come to terms with this reality as evidenced by the growth of “home-based” waivers. These waivers provide in-home and community services to people living with their family.

**Supporting families is the pathway to a sustainable system and a sustainable future.**

The purpose of providing support to families is to strengthen their capacity to support their family member with a disability to have a good life. The more families know, the more robust their network of support and the more secure they are that they are not alone; the stronger will be their capacity to provide support.

Thinking of family in the broadest sense means including siblings, grandparents, other relatives, and sometimes friends of the person and the family. This broad approach to how we think about family multiplies the possibilities for individuals to live in the community they know and to stay close to family members. Supports that are robust, reliable, and portable can make it possible for the person and anyone they have a relationship with [such as] adult siblings, other relatives or friends, to share a life together if they wish.

This is LIFESPAN Work: Individuals with developmental disabilities and their families generally begin the journey at birth and have needs that change across the lifespan.

The Administration on Intellectual and Developmental Disabilities (AIDD) has been engaging stakeholders to facilitate the development of a national agenda and policy recommendations to further elevate the importance of family support [See, [“Building a national agenda for Supporting families with a member with intellectual and developmental](#)



[disabilities](#)," March 2011]

Defining, understanding, and implementing family support in new ways is a core function of state I/DD agencies.

Connecticut and Missouri (page 3, here) have embraced efforts to strengthen their efforts to support individuals and the families they live with in their homes and communities.

[Read full article](#)

## **5. Final Results of the National "Natural Support" Survey**

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**Denver Fox, Ed.D., Parents of Adults with Disabilities in Colorado (PAD-CO) \* April 27, 2011**  
**Purposes and methodology:**

The survey was designed to acquire and share various viewpoints, attitudes, successes, and concerns regarding the controversial topic of "natural supports" for individuals with disabilities and their families/caregivers. Additionally, it was hoped that the results would point to needed further research and studies, which the author believes it has.

In the author's view, "natural supports" has become more prominent in discussions regarding providing services for individuals with disabilities - especially in the presence of long - and perhaps never-ending - waitlists for services, particularly for individuals with intellectual and developmental disabilities. Some have posited that "natural supports" should fill in the gaps, or perhaps even take the place of, paid services for individuals with disabilities.

A simple eight question survey was developed, and on April 13, 2011, emails were sent to a variety of listservs throughout the country. Using a "viral" technique, each recipient was asked to forward the information about the survey to others, achieving input from across the country.

491 survey responses and 304 written open-ended comments were received as of April 25.

2011 and have been posted.

Differing viewpoints regarding "Natural Supports" are illustrated by two selected comments.

Overall results showed that 34% of respondents felt they had strong or moderate natural supports and 66% felt they had little, minuscule or no natural supports. 37.5% felt they had "never" been made to feel guilty by other parents, professionals, service folks, articles in magazines/bulletins, the "system," and/or others regarding level of "natural supports," while 62.5% felt they had "sometime", "frequently" or "a lot" been made to feel guilty by these same audiences.

The most frequent responses to a question asking who provided natural supports were "immediate family," "none that I can think of," and "friends." The least frequent responses to this question were "neighbors," "church," and "social groups."

The website featuring the survey results offers "Level of Support" by "Age of Individual with a Disability," as well as a summary of other findings.

#### [Summary](#)

[The entire survey results with written responses](#)  
[304 written responses to open-ended question 8: "Please provide comments and thoughts about any aspect of 'natural supports' you would like to share. This is an anonymous poll." \(Word format\)](#)

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