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# Representing David: When Best Practices Aren't and Natural Supports Really Are

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## Practitioner's Section: Children's Rights

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This portion of the *Journal of Juvenile Law & Policy* focuses on issues related to children's rights, with an emphasis on the rights of children with disabilities. The journal selected two attorneys to share their insights on practicing law in this area. This section also presents a review of a book that focuses on the negative side of government intervention on behalf of children.

Jennifer Weiser, a staff attorney at Disability Rights Advocates in Berkeley, Calif., examines public resources available to children with disabilities in private religious schools. Stephen Rosenbaum, a staff attorney for Protection & Advocacy, Inc. in Oakland, Calif., and a lecturer in law, discusses the practicalities of best practices when dealing with a developmentally disabled child from the standpoints of both an attorney and a parent.

In this issue's literature review, Justine Dunlap, associate professor of law at Southern New England Law School, critiques *What's Wrong with Children's Rights*, a book by New York University Law Professor Martin Guggenheim. The review examines Guggenheim's critical view of children's advocates and the role they play in securing rights for children.

The Practitioner's Section is followed by summaries of recent court decisions impacting juveniles in the areas of delinquency, dependency, education, and health care.

## REPRESENTING DAVID: WHEN BEST PRACTICES AREN'T AND NATURAL SUPPORTS REALLY ARE

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By Stephen A. Rosenbaum\*

### *Bakarrik ez egotea*<sup>1</sup>

Perhaps it is necessary to be completely removed from one's natural setting to understand what natural supports<sup>2</sup> really means – as in a visit to *Euskadi*, the Basque Country. The scene was Errenteria, a suburb of Donostia,<sup>3</sup> at a folkloric dance contest for the maritime Feast of Our Lady of Carmen. It was a hot July afternoon, and traditionally garbed couples aged 6 to 26 performed intricate *dantzaz* accompanied by a small ensemble of tinny woodwinds. At the end of each number, a distinguishable cheer punctuated the air after the applause had subsided. It was not a cry of anguish, but awkward and noticeable. I turned at one point to see a young man who appeared to have a developmental disability, seated with his older parents in the rear. No one seemed to be the least bit perturbed.

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<sup>1</sup> “Not being alone,” in the Basque language, is one of the objectives of Atzegi, a regional association in the autonomous region of northern Spain, which supports “persons with intellectual disability” and their families. Atzegi is a place where families will be listened to, can share feelings and experiences, and support each other as a group in their struggle for rights. Available at <http://www.atzegi.org> (last visited Nov. 23, 2006).

<sup>2</sup> See, *infra* text accompanying notes 43-54.

<sup>3</sup> More commonly known by its Spanish name, San Sebastian.

After the panel of judges deliberated, and trophies were distributed, the emcee, who spoke only in Basque, called out the names of winning duos. More applause. Berets were tossed and skirts unfurled. Nimble encores were performed. At one point, heads turned and the young man who had cried out was walking toward the stage, followed by his parents, who had tears in their eyes. Curious, we asked our fellow audience members, in Spanish, just what was going on. The judges had awarded this young man a trophy for being the most enthusiastic fan. It seems he regularly attended these contests and was as intrigued as first-time tourists like ourselves.

As the crowd was breaking up, parents and friends of dancers held in their hands the gleaming trophies. These same proud parents and friends gathered around The Most Enthusiastic Fan to admire the prize awarded to him. They were not feigning interest, and in fact appeared to know him and his family. It was spontaneous, unprompted and as authentic as the traditional dances, costumes, and language. Now, that's what I call natural support – and not being alone.<sup>4</sup>

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As California marks the 30-year anniversary of the Lanterman Developmental Disabilities Services Act,<sup>5</sup> there is more legal support and social acceptance than ever for including individuals with developmental disabilities in our daily lives. At the click of a mouse, there is an abundance of information about related services, rights, and resources. Yet, the day-to-day decisions are not necessarily easier. As informed parents and professional advocates, we are meant to digest the latest literature, absorb the best practices, fight the fights, rise above the loneliness, and travel the correct path in our search for services and support. From early intervention to

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<sup>4</sup> See, *supra* note 1. Language matters.

<sup>5</sup> Stats. 1977, c. 1252, p. 4521 § 550. CAL. WELF & INST. CODE § 4500 *et seq.* (West 2005) See, *infra* text accompanying notes 7-19 for a description of the act.

respite care, from residential placement to transition-planning and natural supports, I have traveled that path, strayed from it, and learned a few things along the way.

In this article, I highlight the peculiar difficulties posed for professionals like myself, who advocate on behalf of our own children with disabilities, using the Lanterman Act as a backdrop. Mindful of the best practices to which we all aspire, our advocacy is bracketed by the realities of time, money, bureaucratic behaviors, and human or other subjective factors. And so it was – and is – with my son David. This could be read as a manifesto for understanding and compassion from peers – traits that go as far as legal knowledge, enhanced consciousness, and ideology in helping to shape the model disability rights advocate.

### **The Lanterman Act: Making It More Than a Piece of Paper<sup>6</sup>**

The Individualized Education Program (IEP)<sup>7</sup> is familiar to most lawyers and lay advocates whose clients are disabled students.<sup>8</sup> Its less well-known counterpart is the Individual Program Plan (IPP). Just as the IEP determines the placement and constellation of educational services a California youngster<sup>9</sup> receives, the IPP is the key document

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<sup>6</sup> “Your IPP: It’s Not Just a Piece of Paper” is the name of a PAI consumer publication, written jointly with Capitol People First. The easy-to-read guide explains the Individual Program Plan process, including regional center case management and services coordination for Californians with developmental disabilities. *See also*, the more detailed *Rights Under the Lanterman Act*, available at <http://pai-ca.org/PUBS/503801.htm>.

<sup>7</sup> The Individualized Education Program is the statement of a disabled student’s educational needs and specific goals and methodologies for meeting them, required under the Individuals with Disabilities Education Act (IDEA), and written by a team of parents, school personnel, and others. 20 U.S.C. § 1401(14) (2006); Cal. Educ. Code § 56340, *et seq.* (West 2005).

<sup>8</sup> On the IEP experience and suggested advocacy approaches, *see* Stephen A. Rosenbaum, *When It’s Not Apparent: Some Modest Advice to Parent Advocates for Students with Disabilities*, 5 U.C. DAVIS J. JUV. L. & POL’Y 159, 171-86 (2001) (hereinafter, *When It’s Not Apparent*).

<sup>9</sup> Cal. Educ. Code § 56000 *et seq.* (West 2005), which refers to students as “individuals with exceptional needs,” mirrors the federal IDEA. I have

when it comes to supports and services that persons with *developmental* disabilities receive in their pre-school and adult years, and in all matters outside the schoolhouse door.<sup>10</sup>

The Lanterman<sup>11</sup> Act is the nationally renowned legislation which, through the IPP, accords Californians with developmental disabilities the right “to make choices in their own lives.”<sup>12</sup> This is accomplished with the aid of a network of quasi-governmental “regional centers” that contract with the state. The determination of necessary services and support is based on “the needs and preferences of the consumer or, when appropriate, the consumer’s family, and shall include consideration of a range of service options proposed by [IPP] participants.”<sup>13</sup> With my son, we were fortunate to avoid meetings with 20 team members – assorted specialists, program managers, therapists, and psychologists – assembled

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previously urged that *all* students should be entitled to an individualized learning plan. *When It’s Not Apparent*, *supra* note 8 at 161, n. 12.

<sup>10</sup> Developmental disabilities, such as mental retardation, autism, epilepsy or cerebral palsy, are manifested before adulthood and reflect a need for lifelong or extended forms of assistance. The disability results in three or more “substantial functional limitations” in “areas of major life activity,” *viz.*, self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. See 42 U.S.C.A. § 15002(8) (West 2005) and CAL. WELF & INST. CODE § 4512(l) (West 2005).

<sup>11</sup> As Republican State Assembly Member Frank Lanterman’s legacy extends beyond this statute – to other disability rights legislation, and a developmental center and regional center named in his honor – it is fitting to speak of Lanterman the Man, the Act, the Buildings – and coming soon, perhaps, the DVD.

<sup>12</sup> *Id.* at § 4502.1 (West 1998).

<sup>13</sup> *Id.* at § 4512(b) (West 2006). Services and supports – not cash benefits – are “directed toward the alleviation of a developmental disability or toward [one’s] social, personal, physical, or economic habilitation or rehabilitation ... [or] the achievement and maintenance of independent, productive, normal lives.” The statute lists a dizzying array of possible training, therapies, equipment, and care which must be both effective and cost-effective in meeting one’s IPP goals. *Id.* The services are coordinated by private nonprofit community agencies that operate “regional centers.” *Id.* at § 4620 (West 1998). These centers serve developmentally disabled consumers in 21 geographic regions in California. The services are not based on income, although there may be a co-payment, and are meant to supplement other public and private services and supports. *Id.*

at the table who would attempt to scrutinize, analyze, categorize, and program David. I routinely caution parents about that kind of meeting, where there may be a cast of thousands, and a low level of productivity and candor.<sup>14</sup>

Like the federal and state special education statutes, the Lanterman Act is filled with mandates for services and parental and consumer rights.<sup>15</sup> The entitlements for youngsters – and adults – with developmental disabilities are the result of many years of parental activism and lobbying. The text is well crafted, and much of the interpretive jurisprudence is favorable.<sup>16</sup>

However, enforcing these provisions requires funding and a good deal of vigilance. In addition to creating regional centers, the California legislature also established a number of “area boards” throughout the state to monitor the state’s federally mandated five-year plan for service delivery and technical assistance to people with developmental disabilities.<sup>17</sup> It also acknowledged the broad authority of the

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<sup>14</sup> Size matters, or so it seems with administrators (and sometimes parents), who insist on summoning a gaggle of school personnel to a meeting, at least for a child’s IEP. In the early days of the federal special education law, one commentator observed that “[t]he more parties involved in the plan ... the less likely it is to be meaningful.” Eugene Bardach, “Educational Paperwork,” in David L. Kirp & Donald L. Jensen, eds., *School Days, Rule Days* 128 (1986). The IPP may actually suffer from a lack of attendance, or take the form of a quickly-convened “meeting” on paper.

<sup>15</sup> At the heart of the act, like the (developmental) disability movement itself, is the principle of *choice*. All agencies receiving state funds “shall respect the choices made by consumers or, where appropriate, their parents, legal guardian, or conservator [and] shall provide consumers with opportunities to exercise decision making skills in any aspect of day-to-day living.” CAL. WELF & INST. CODE § 4502.1 (West 2005).

<sup>16</sup> See, e.g., *Ass’n for Retarded Citizens v. Dep’t of Developmental Services*, 38 Cal. 3d 384, 388 (1985) (Lanterman Act is “a comprehensive statutory scheme ... to provide a ‘pattern of facilities and services ... sufficiently complete to meet the needs of each person with developmental disabilities ... [and] to enable them to approximate the pattern of everyday living of nondisabled persons of the same age and to lead more independent and productive lives in the community [citations]”).

<sup>17</sup> CAL. WELF & INST. CODE § 4543(a) (West 2005). The State Council on Developmental Disabilities is responsible for preparing and monitoring a

state affiliate of the national protection and advocacy system to ensure the legal, civil, and service rights of developmentally disabled individuals.<sup>18</sup> Of course, consumers, parents, and other family members also play an important role in oversight and advocacy of individuals with developmental disability.

### Dis-Awareness

On the spectrum of the phenomenon I call “dis-awareness,”<sup>19</sup> at one end is the silence, isolation, or absence of information and communication about disability in the legal community. At the other end is consciousness about, and sensitivity toward, disability.<sup>20</sup> A more nuanced dis-awareness comes from the well-meaning, but overly zealous and blithe, professionals and activists, who espouse an *uber*-awareness.

In the end, this latter awareness also suffers from insensitivity and facileness. It sends a message to the families and loved ones of persons with disabilities – who may also be

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state plan for the expenditure of federal funds received pursuant to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15001 *et seq.* (West Supp. 2006).

<sup>18</sup> CAL. WELF & INST. CODE § 4901(a) (West 2005). The California agency is PAI. *See, generally* <http://www.pai-ca.org>. *See also*, 42 U.S.C. § 15043(a)(1)-(2) (West 2005) (state shall have system to protect and advocate for the rights of individuals with developmental disabilities ... to pursue legal, administrative, and other appropriate remedies). In recognition of bureaucratic realities and the need for oversight and advocacy, the legislature also made a finding “that the mere existence or the delivery of services and supports is, in itself, insufficient evidence of program effectiveness.” CAL. WELF & INST. CODE § 4501 (West 2005).

<sup>19</sup> Patricia A. Massey & Stephen A. Rosenbaum, *Disability Matters: Toward a Law School Clinical Model for Serving Youth with Special Education Needs*, 11 CLIN. L. REV. 271, 285-94 (2005). While the article focuses on shortcomings in law school teaching, scholarship and clinical education, and the attempts at redress, the academic institution can be seen as a microcosm for the profession at large, with respect to dis-awareness.

<sup>20</sup> *Id.* For some attorneys who don’t practice in this area, there is a certain glamour or allure. It was both amusing and flattering to receive an email from an ACLU law graduate fellow who wrote in anticipation of her first IEP meeting: “I am just grateful that you are able to talk us through this a little as we suit up for our ‘TV roles as disability rights lawyers.’” E-mail from J.L. (Oct. 17, 2006) (on file with author).



colleagues – that there is one correct model for habilitating,<sup>21</sup> educating, living, and caring, and it often bears the label of “best practices.” This dis-attitude approaches hubris, and runs counter to the very byword of the disability rights and independent living movements: choice.

This is not a bitter rebuke, but a plea for tempering our ardent advocacy with realism and respect. And, while I write from the perspective of the self-conscious professional wanting to do the right thing for my kid, it is a message that transcends my particular parental status. It is a message for all those who aid disabled<sup>22</sup> children in the legal assistance arenas.

### Unnatural Environments

Under current state regulations, services to disabled infants and toddlers are to be offered in “settings that are natural or typical for the infant or toddler’s age peers who have no disability, including the home and community settings

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<sup>21</sup> This is akin to *rehabilitating*, although it is about starting – not starting over. In plain English, we might say “skills training.” *Habilitation* is part of the vocabulary one acquires, like *challenging* and behaviors, when entering the world of developmental disability jargon. See CAL. WELF & INST. CODE § 4502(a) (West 1998) and § 4851(a) (West 2006) for a more precise definition.

<sup>22</sup> Language matters. For the sake of brevity, variation, and perhaps perversity, I occasionally use “disabled” as an adjective – to the chagrin of purist colleagues who eschew this in favor of “people first” language. While “person with a disability” accentuates the humanity, and not the impairment or disabling condition, some activists and academics use “disability first” language for emphasis, or to reclaim with pride pejorative terms. See Stephen A. Rosenbaum, *Aligning or Maligning? Getting Inside a New IDEA, Getting Behind No Child Left Behind and Getting Outside of It All*, 15 HASTINGS WOMEN’S L.J. 1, 4 n.14 (2004) (hereinafter *Aligning or Maligning?*). See also, Richard Fung, *Looking for My Penis: The Eroticized Asian in Gay Video Porn*, in *Bad-Object Choices*, eds., HOW DO I LOOK? QUEER FILM AND VIDEO 168, n.8 (1991) (“too much time spent on the politics of ‘naming’ can in the end be diversionary”). But see, “Why ‘Voice of the Retarded?’ A Statement About our name,” [http://www.vor.net/name\\_game.htm](http://www.vor.net/name_game.htm) (last visited Nov. 23, 2006) (leaders aware that maintaining “the retarded” in organization’s name not “politically correct,” but “[t]he ‘buzz’ we are all witnessing relates mostly to debate within disability circles”).

in which children without disabilities participate.”<sup>23</sup> The Parent-Infant Program at Children’s Hospital was not a “natural environment” when my son David was a baby. That term had not yet even entered the early intervention disability lexicon.

Our children are so often reduced to scores and percentiles, levels of performance, and adjudicatory outcomes. At doctors’ visits and IPP team meetings, the reports would always begin, “This young man presents as . . .,” and we would read for the umpteenth time about David’s birth weight, his complicated and traumatic delivery, and his hypertonic (or was it *hypotonic*?) muscle tone. The numbers stood out on page 8 of the staff psychologist’s report:

**Age equivalent = 0.8 months.**

The hospital program, however, was a safe space where one could engage in play-like activities without sensing the pitying glance or curious gaze of those whose children did not need therapeutic interventions. My partner and I could take refuge amongst David’s typically developmentally disabled peers and their typically developed parents. We did not need to offer explanations, or smiles and cheers for the seemingly effortless feats of the non-disabled children who inhabit natural environments.

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<sup>23</sup> 17 C.C.R. § 52000(b)(35) (2006). See 34 C.F.R. Pts. 300.114 – 300.118 (2006). “To the maximum extent appropriate, children with disabilities . . . are educated with children who are nondisabled.” *Id.* Pt. 300.114(a)(2)(i). We were more prepared, and even eager, to face the integrated school milieu, after having spent earlier years in an admittedly more sheltered setting. Some “best practices” promoters dismiss the “readiness” or sheltered training approach, insisting that there is no need for a disabled person to *practice* before entering the real world. Perhaps the *parents* need more time to adjust. See also, 20 U.S.C. § 1432(4)(G) (2006) (under IDEA, early intervention developmental services are provided, according to a Individualized *Family Services Plan*, for children ages 0-3 at risk of substantial developmental delay). The “inclusion” or “integrated” model was first introduced in the elementary schools and K-12 schools generally, as an interpretation of the “least restrictive environment” principle under IDEA.

After the songs and circle time, the painting and gymnastics, caring and competent adults would watch our children for a bit while we retreated onto worn couches in a back room to munch on store-bought sandwich crèmes and sip weak coffee. We tried to make sense of our world with the help of a facilitator. What followed were tears, hopes, and fears. We were segregated, but protected.

### **When Respite Isn't Enough**

“To relieve parents from the ‘constantly demanding responsibility of caring’ for a child with a developmental disability.” That is one of the stated purposes of in-home respite care, a classic Lanterman Act support (or is it a *service*?). Defined as “intermittent or regularly scheduled temporary non-medical care and supervision provided in the consumer’s own home,” respite care is designed to assist family members in maintaining a disabled youngster at home, thereby avoiding residential placement.<sup>24</sup> Some may refer to it as glorified babysitting, but it really requires more extraordinary skills on the part of the caregiver, especially in the case of older youths, for whom it is not “cool” or appropriate to have a babysitter. Under the Lanterman Act, parents in search of respite care have a right to a provider who will attend to their child’s basic self-help needs, safety, and other activities of daily living usually performed by a family member.

The “constantly demanding care” required by a disabled child can be a bit of an understatement. The word “care” does not begin to describe the vast amounts of time parents might spend monitoring the various therapies and appointments. Virtually all parent-child interactions are

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<sup>24</sup> See 17 C.C.R. § 54302(a)(38) (2006). In legislative findings and an explicit mandate to regional centers, the Lanterman Act declares unequivocally that, for social, educational, and fiscal reasons, developmentally disabled children are best provided for at home with their families. CAL. WELF & INST. CODE § 4685 (West 2005). In particular, the state’s developmental services department and contracting regional centers are to give “very high priority” to developing and expanding services to assist families caring for their children at home. *Id.* at § 4685(c)(1). See also *Williams v. Macomber*, 226 Cal.App.3d 225, 233 (1990) (Lanterman Act declares “in strong terms” need to assist family in caregiving at home).

intentionally and intensively therapeutic.<sup>25</sup> It was only later in my fatherhood – when I became a full-time disability rights lawyer – that I learned why a child’s “behaviors” take the plural form and are sometimes euphemistically referred to as “challenges.”

It was so important for us in David’s early years, and as he entered his teens, to have someone relieve us from direct care so that we had time for one another and for our other two children (not to mention outings and invitations, or mundane chores that could not be accomplished with David in tow). By law – and presumably best practice and the natural order of things – respite care was intended to preserve family unity and sanity, and to avoid out-of-home placement.

Yet, no policymaker or ultra-correct advocate takes account of the stress on the family of having some new person come into your home. There is the matter of scheduling: anticipating needs many weeks in advance, making sure a suitable caregiver is available and cramming one’s errands, appointments, or outings into that fixed time block of inadequately allocated respite hours.<sup>26</sup> Then there are concerns about the caregiver showing up on time, or at all. And, once you have trained a caregiver who is competent, you worry he will move on because the pay is so paltry (despite our ability to supplement the standard rate), which means having to start over.

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<sup>25</sup> See, e.g., the experience of the mother of Katie, a Down Syndrome child, who “executed therapy goals every minute of the day ... There was never a moment [Katie] wasn’t stimulated.” Leslie Kaufman, “Just a Normal Girl,” *New York Times, Education Life* 24, 26 (Nov. 4, 2006). “I just didn’t have time for friends,” she explained. *Id.*

<sup>26</sup> Each regional center has a policy for allocating respite care hours. See, e.g., *Matter of C.L. v. Central Valley Regional Center 5* (Off. of Admin. Hrgs. No. 2001050032), available at <http://www.oah.dgs.ca.gov> (regional center respite guidelines – using points assigned to consumer’s behavior, care needs, adaptive functioning, and family circumstances to establish level of service – cannot be fixed and inflexible). It has almost become urban legend in the regional center system that service coordinators “hide the ball” from parents on the availability of respite care.

There are no provisions in the act to account for the aches we endured because we couldn't do the normal things that families did together. Or the guilt we felt for not always taking David where we would take our other children. It was not because we were ashamed to bring our son and his behaviors. Rather, each venture outside the home brought a series of (sometimes selfish) questions: What benefit would David derive? What kind of one-on-one care or support could we provide?<sup>27</sup> How much would his presence detract from our own enjoyment – or that of his siblings or those around us? Who will read aloud to these people the Developmental Disability Bill of Rights?<sup>28</sup>

In earlier “unenlightened” times, there would be no agonizing and no regrets about leaving one's disabled child behind – at home, or, more likely, in some far-off red-brick institution with a bucolic or pious name over the entry gate. Today, we have the law, changing social attitudes, and best practices about choice and independence as our guideposts. This does not always jibe with one's own reality. When my partner and I made the difficult decision to consider the “P” word – Placement – I knew this was not what Lanterman or The Movement had intended. Nonetheless, the limited allotment of hours and quality of intermittent respite care was not really enough of a service – and there was no other support, natural or otherwise, to keep David at home.

### **Building a “Six-Pack”?**

What I really meant to write is “Six-Pack”?!@\*&^%? The term is disrespectful, degrading, and demoralizing. Yet, it rolls off the tongues of fair housing and disability lawyers when they describe community care facilities that house six

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<sup>27</sup> Even as I write a final draft of this article, my adult son, at home for Thanksgiving, is not necessarily able to care for or amuse himself for a sustained period of time without interaction or assistance.

<sup>28</sup> CAL. WELF & INST. CODE § 4502 (West 2005). *See also* 42 U.S.C. § 15009 (West 2005). Among the articulated rights are appropriate treatment, services, and habilitation “designed to maximize the potential of the individual ... in the setting that is least restrictive of the individual's personal liberty.” *Id.* at § 15009(a)(2).

people – people who are “placed” there by a parent or conservator. For some, these group homes are damned as institutions. To frame the debate in terms of institutionalized vs. community-based, or segregated vs. integrated, however, is misleading and disingenuous. I have yet to find a satisfactory definition of institution.<sup>29</sup> As for “the community,” it is a concept susceptible to a variety of interpretations ranging from the cynical to the cryptic, and the abstract to the abstruse.<sup>30</sup> It is important to look beyond the four walls and the superficial settings of the facilities to discover the real meaning of inclusiveness and independence.<sup>31</sup>

Yes, children should live at home with their parents and, for adults with disabilities, “supported living” may be the preferred option. Supportive living services help regional center consumers live in their own homes “with support available as often and for as long as it is needed” and “[m]ake fundamental life decisions, while also supporting and facilitating the consumer in dealing with the consequences of

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<sup>29</sup> Again, size matters. Colleagues litigating for the transfer of more Californians from state developmental centers and other congregate facilities to community-based homes define a large institution as a facility with more than 16 beds. *Capitol People First v. Dep’t of Developmental Services* (Alameda Co. Sup. Ct. No. 2002-038715), Am. Pet/Pfs’ Memo. of Pts. & Auth. in Support of Mo. for Class Cert. 15 (Sept. 29, 2005), available at <http://apps.alameda.courts.ca.gov/fortecgi/fortecgi.exe?ServiceName=DomainWebService&TemplateName=index.html>. I rather belatedly discovered that my office’s standard intake form has a field labeled client’s “living arrangement” in which a *large* group home is defined as more than *three* beds. Does that make it an *institution*?

<sup>30</sup> Not everything is rosy in the community, nor everything bleak in institutions. See, e.g., Michele R. Marcucci “Agency is Sued in Rape of Client; Suit: Care Provider Didn’t Ensure Safety,” available at [www.mercurynews.com/mld/mercurynews/news/local/16120878.htm](http://www.mercurynews.com/mld/mercurynews/news/local/16120878.htm) (visited Nov. 29, 2006) (supported living agency charged with negligence in rape of woman who has mental retardation) and “Letter to the Editor,” *Sonoma-Index Tribune* (March 4, 2005) (“I was expecting Frankenstein-like treatment at best, and more likely neglect and abuse [when entering developmental center]. I was wrong”).

<sup>31</sup> San Francisco State University Historian Paul Longmore has wisely observed, in conversation on more than one occasion, that the real goal for the disability rights movement, and our society in general, is not independence, but *interdependence*.

those decisions; building critical and durable relationships with other individuals; choosing where and with whom to live; and controlling the character and appearance of the environment within their home.”<sup>32</sup>

I am in total agreement with the Lanterman Act's legislative language and its intent to normalize the residential expectations of persons with developmental disabilities. But, David is not really suited for supported living. It made no sense economically or programmatically to have my son in his own apartment with around-the-clock staffing, given his self-care needs – and that doesn't even take into account his personality. Many adults and youth, like David, like the company of others and actually enjoy communal living, particularly if they are apart, or estranged, from their nuclear or extended family.<sup>33</sup>

Yet, the high price of urban real estate and cost of living make for fewer group homes located in desirable metropolises so that a disabled person might be near to family and friends. The funds available to regional center consumers based on state-determined reimbursement rates<sup>34</sup> simply do

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<sup>32</sup> 17 C.C.R. §58614(a) (2000). *See, generally, id.* § 58600, *et seq.*, for regulations governing supported living services schemes.

<sup>33</sup> As a graduate student, I was content to live with five other adults – including my future spouse – in a weathered Queen Anne's house on Lorina Street, sharing meals, celebrations, rituals, and party guests, as well as domestic chores, transportation, rental payments, and even hallowed house meetings. Congregate living doesn't seem to have a bad reputation when it involves non-disabled college students or 20- and 30-somethings, not to mention co-housing residents or seniors.

<sup>34</sup> On rate-setting procedures for community-based developmental disability programs, *see* 17 C.C.R. § 56900 *et seq.* (2005). One of the complaints that fellow advocates have expressed about congregate facilities is that they are “staffed.” Ideally, every housing unit, including those officially designated for supported living, would rely on natural supports (*see infra* text accompanying notes 43-54) to accomplish day-to-day tasks and supply all the other comforts of a home. In fact, the residential, respite, vocational, habilitative, and educational service delivery system would totally collapse without staff. That is not to say that hiring and retaining competent paraprofessionals is a simple matter, whether the setting is “integrated” or “segregated.”

not keep pace with mortgages, staff wages,<sup>35</sup> or other operational costs. This affects small-scale, community-based homes, as well as apartments or duplexes that might be appropriate for supported living candidates. For those few homes with a vacancy, situated within a reasonable distance and managed by qualified staff, it is difficult to negotiate much family involvement in the day-to-day affairs of a “second residence,” except in the most cursory ways.

As real world costs and other considerations intruded on our dreams and the theoretical models, we were left with few options. After a good deal of politicking and fundraising, we helped build – that is to say, bought and rehabilitated – a home, a state-licensed care facility for *six* people, under the auspices of BUiLD, Inc.<sup>36</sup> David and five others now live in a turn-of-the century home (remodeled using universal design principles) set on a modest residential block, with other nuclear family residents and apartment dwellers, and a half-dozen houses down from the Rosa Parks Elementary School. It takes less than five minutes to walk or roll to a bus stop, and perhaps 10 minutes to get to the trendy Fourth Street shopping district.<sup>37</sup>

The underlying fear of my well-meaning, but misguided, colleagues is that parents may make the wrong

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<sup>35</sup> A recent innovation in community-based service delivery is the “professional employer organization,” an intermediary designed to ease costs and administrative burdens for provider agencies, professionalize the workforce, and improve wages and work conditions for the individual support workers and caregivers, largely through unionization. For more on this model, see Carol Zabin, *Quality Services and Quality Jobs for Supporting Californians with Developmental Disabilities*, 24 *et seq.*, (UC Berkeley Center for Labor Research and Education 2006), available at <http://laborcenter.berkeley.edu>.

<sup>36</sup> Berkeley Youth Living with Disabilities, Inc. (BUiLD) owns and operates a licensed, intermediate care facility. See, generally <http://www.buildhouse.org>.

<sup>37</sup> The process was not without obstacles, including some resistance from Not-In-My-Back-Yard neighbors and a retailer who said, “This cannot come in here,” in reference to a wheelchair-using BUiLD resident. The neighbors are now on good terms and the merchant agreed to an out-of-court settlement, including sponsorship of a workshop on anti-discrimination laws for area small businesses.



choice about so-called institutionalization.<sup>38</sup> The lack of sensitivity to the feelings of parents in general was decried more than 25 years ago by the first-generation deinstitutionalization-oriented researchers. They noted the irony that activists who championed the human dignity of individuals with mental retardation would at the same time devalue the human dignity of these people's parents.<sup>39</sup> What has the potential as a solidarity movement for change can easily deteriorate into stakeholders locked into caricatured and uni-dimensional stances. The activists spend more time sloganeering and vilifying each other than joining in common cause to battle the bureaucratic or fiscal inadequacies of the social services system.<sup>40</sup> Moreover, little is done by the

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<sup>38</sup> At a recent PAI staff workshop on litigation strategy, one lawyer participant expressed concern that a parental satisfaction settlement monitoring scheme might result in parents actually preferring a so-called institutionalized living setting to one that is community-based. Again, there is the fear that parents may make the wrong choices.

<sup>39</sup> Robinsue Frohboese & Bruce Dennis Sales, *Parental Opposition to Deinstitutionalization: A Challenge in Need of Attention and Resolution*, 4 L. & HUM. BEHAVIOR 1, 2 (1980).

<sup>40</sup> See, e.g., the evolution of the National Association for Retarded Citizens or ARC (now simply "The Arc") from service provider to advocate for community-based alternatives to institutionalization and the eventual schism among state chapters between parents who supported, and opposed, large-scale removal of persons with developmental disabilities from state institutions. *Id.* at 18, 25-26. The California Association of State Hospital Councils of Parents for the Retarded (CASH/CPR) is one of the oppositional organizations that progressives love to hate. See, generally, <http://www.cashpcr.org>. The de-institutionalization debate was recently reignited over closure of the historic Agnews Developmental Center, with parties such as CASH/PCR and PAI assuming some of their equally historic roles. See, e.g., Michele R. Marcucci, "Abuses Found At Some Group Homes," *Oakland Tribune* (Dec. 21, 2003) (Keep Our Families Together coalition concerned that if "forced to place their loved ones in the community, the health and welfare and safety of those clients is going to be in jeopardy"). See also, Cal. Alliance for Inclusive Communities, Inc., *Advocates Applaud Schwarzenegger Plan To Close Agnews Developmental Center* (closure can serve as "model for developing a comprehensive statewide plan to help these people who are still confined in institutions and don't have to be. People with disabilities should not be forced into segregated institutional care because there is no alternative"). Available at <http://www.caic.org/AgnewsClosure.htm> (last visited Nov. 27, 2006).

advocacy community to bridge the concerns of these two camps, much less genuinely wrestle with competing philosophical or pedagogical views.<sup>41</sup>

### Support That is Natural and Embracing

With all the emphasis on person-centered planning,<sup>42</sup> it is easy to ignore the benefits of a *family*-centered approach to planning, even when it does not involve disabled minors. Other social and educational support systems have taken into consideration family strengths, acknowledging them, incorporating them into intervention plans, and building upon them.<sup>43</sup>

According to this model of family-centered service delivery, family members are in the best position to judge whether services are indeed family centered and to determine if they successfully meet their needs. Professionals must learn to trust families – to trust that they have strengths, they genuinely and deeply care for their children, they are

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<sup>41</sup> Joining the institution closure clash was Assembly Human Services Committee Chair Noreen Evans, whose legislative district includes the Sonoma Developmental Center. Evans issued a press release lambasting the Schwarzenegger administration and local regional center for imposing illegal quotas for transferring people from Sonoma, “cast[ing] aside their care needs and the wishes of their families ... because they require changes in services that may jeopardize the quality of care for our developmentally disabled.” “Evans Exposes Administration Cover Up: State Victimized Developmentally Disabled and Their Families” (Oct. 25, 2006), available at <http://democrats.assembly.ca.gov/members/a07/press/a072006029.htm>. PAI spearheaded an open letter to the legislature in response, available at <http://www.pai-ca.org> (visited Nov. 23, 2006).

<sup>42</sup> CAL. WELF & INST. CODE § 4646 (West 2005). See also, “Your IPP: It’s Not Just a Piece of Paper,” *supra* note 7 and Calif. Dep’t of Developmental Services, INDIVIDUAL PROGRAM PLAN RESOURCE MANUAL: A PERSON-CENTERED APPROACH (2000).

<sup>43</sup> See, e.g., Reva I. Allen & Christopher G. Petr, *Toward Developing Standards and Measurements for Family-Centered Practice in Family Support Programs*, in G.H. Singer, L.E. Powers & A.L. Olsen, eds., *Redefining Family Support: Innovations in Public-Private Partnership* (1996). The family-centered approach “modifies the view of family members as people who only cause problems and are obstacles to the improvement of clients, and it is consistent with the notion of collaboration as a preferred style of family-professional interaction.” *Id.* at 65.

interested in and capable of growth, and can make effective decisions on their own behalf. They must also actively reinforce the process of sharing information with family members so that their decisions may be as informed as possible.<sup>44</sup>

It would seem to follow from a family-centered approach, or at least family participation in planning, support, and advocacy, that the concept of “natural supports” embraces a family component, particularly for youth and young adults with developmental disabilities. The Lanterman Act characterizes natural supports as those “personal associations and relationships typically developed in the community that enhance the quality and security of life for people.”<sup>45</sup> It explicitly refers to family, as well as friends, fellow students, co-workers, and “associations developed through participation in clubs, organizations, and other civic activities.”<sup>46</sup>

It is not readily apparent how these natural supports differ from what the act calls a “circle of support.” The latter is “a committed group of community members, who may include family members, meeting regularly with an individual with developmental disabilities in order to share experiences, promote autonomy and community involvement, and assist the individual in establishing and maintaining supports.”<sup>47</sup> Generally, these individuals are volunteers who are not themselves developmentally disabled.<sup>48</sup>

Added to the statutory and regulatory guidance is this bland recipe from the Department of Developmental Services:

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<sup>44</sup> *Id.* at 74.

<sup>45</sup> CAL. WELF & INST. CODE § 4512(e) (West 2005).

<sup>46</sup> *Id.*

<sup>47</sup> *Id.* at § 4512(f).

<sup>48</sup> *Id.* No doubt someone somewhere is defending a dissertation in which these nuanced forms of support are discussed and deconstructed. For a tidier and slightly different definition of “circle of support,” *See* 17 C.C.R. § 58601(a)(1) (2000) (“informal but identifiable and reliable group of people who ... meet and communicate regularly to offer support, at a frequency and in a manner consistent with and appropriate to the [person’s] need”).

There is no single method or easy answer for developing a system of natural supports. It's a matter of supporting and assisting consumers to be in a position to develop associations and relationships. The activity of someone assisting in developing natural supports for a consumer is in devising strategies to bridge the gap between the opportunities for, and development of, natural supports. It may require considerable time to develop and nurture natural supports. But we know if we do nothing, we'll have nothing. The possibilities are endless, given some creativity and willingness.<sup>49</sup>

Does any of the best practices chimera or sermonizing about supports rub off on the educators, therapists, facilitators, and other service providers in the trenches? One college counselor, referring to a young woman with Down Syndrome attending a regular college program, offered this bleak assessment: "Katie thinks she has a million friends, but she is going to leave here and not one student is going to stay in touch."<sup>50</sup> While this smacks a bit of cynicism or overstatement, there may be some sobering truth.

Our local high school had a "best buddy" club, and for a while David actually had a best buddy. I always found the term a bit patronizing, but these dis-aware high school kids (in the best sense of the word) were earnest and friendly, and there were some fine opportunities for socializing and consciousness-raising. However, after some 15 years of inclusive education in a school district that once had a

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<sup>49</sup> Department of Developmental Services, *Natural Supports ... They're All Around You!* (June 20, 2006), available at [http://www.dds.cahwnet.gov/publications/PDF/Natural\\_Supports.pdf](http://www.dds.cahwnet.gov/publications/PDF/Natural_Supports.pdf).

<sup>50</sup> Kaufman, *supra* note 25 at 26. This counselor's skepticism about future friendships is obviously debatable. But, whether those relationships in fact continue, it does not follow that Katie would be better off in classes or social groupings solely with other Down Syndrome students.

partnership<sup>51</sup> with a respected institution of higher education and some of the “full inclusion” pioneers, it is a struggle to get the district and regional center to assemble a meaningful, person-centered, post-secondary transition education program for my son.<sup>52</sup> The team members sometimes “talk the (augmented communication) talk,” but rarely “roll the roll.”

This does not even begin to address the question about natural support outside of school or when he is issued his certificate of completion next year. When he was younger, David would be invited to birthday parties, and happily at that. That phase soon passed. One long-time classmate would chat him up on the high school campus and various instructional aides became attached – and vice-versa – and took David to a concert or even skiing outside of school hours. But, a series of high-fives and “Hi, Daves” does not a circle of support make. While Katie, the college student with Downs, may lose her natural supports once she graduates, David has no peer right now to hang out with on weekends, not to mention after he leaves his bungalow.<sup>53</sup> And will there be a special someone later on to share an iPod® headset or someone who will try to hook up with him?

### Lessons Learned

What it comes down to is choice. And respecting the choices made by others. It is as easy for me to make

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<sup>51</sup> They might use words like “partnering” or “a collaborative” to describe the relationship; I’ll stick with traditional nouns.

<sup>52</sup> See 20 U.S.C. § 1401(34) and § 1414 (d)(1)(A)(i)(VIII) (2006) (defining transition needs and services for students 16-22 years of age related to training, education, employment, and independent living skills). See also Cal. Educ. Code § 56460(e) (West 2003) (“Planning for transition from school to post-secondary environments should begin in the school system well before the student leaves the system”); *Id.* at § 56462 (West 2003) (description of transition program, resources, and curriculum); See also, California Services for Technical Assistance and Training (CalSTAT), Sonoma State University, *The Transition to Adult Living: A Guide for Secondary Education* (2003), available at <http://www.cde.ca.gov/sp/se/sr/>.

<sup>53</sup> Ironically, after being educated in regular classrooms from kindergarten through 12th grade, Dave and his fellow transition ex-included students are located for a better part of the day in a classroom bungalow; that quintessential symbol of segregated special ed.

assumptions about other disabled kids and their parents as it is for parents, lawyers, and other advocates to make assumptions about me and my child. For some the child is a blessing, and for others he is a burden. I expect that adults with disabilities might take exception to these characterizations, as parents of disabled offspring and people with disabilities can and do end up on different sides. And, notwithstanding the romanticized images, not all people with disabilities struggle in solidarity.<sup>54</sup>

Adhering to the professional ethic in an age of expanding disability consciousness and law can be challenging for the attorney-parent – or indeed any parent of a disabled child – when coupled with the mundane realities of daily life. We are advocates and case managers, service providers and natural supporters. Sometimes we work alone, and sometimes we work in concert with others. We welcome advice and support, when appropriate. But, in the end, we simply long to be parents doing what we can to get by.<sup>55</sup>

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<sup>54</sup> “Although the promoters of disability civil rights may pride themselves on being members of a cross-disability movement, there are very real differences in the experience of the teen with cancer, the child who has significant cognitive impairments, and the adult resident of a psychiatric institution.” Massey & Rosenbaum, *supra* note 19 at n. 101.

<sup>55</sup> This sentiment is reflected in curricular materials for students training to be special education lay advocate trainees in a U.S. Department of Education-funded pilot project. Advocates are actually reminded to respect and understand the complexities of their parent-clients’ lives and to communicate in honest and non-judgmental ways. University of Southern California University Ctr. for Excellence in Developmental Disability-Council of Parent Attorneys & Advocates, *Special Education Advocate Training Demonstration Project Manual* at 4-29 to 4-31 (August 2006 Instructor’s Manual) (on file with author).