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Parental Caregivers’ Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities

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Future life planning is a growing concern among families with children with disabilities. This article presents a needs assessment evaluating feasibility of a new model for future life planning for family caregivers, Lifetime Assistance, which will provide ongoing planning and monitoring for individuals with intellectual and developmental disabilities. Using surveys informed by a series of focus groups, data were gathered from older and younger parents in one midwestern state regarding the potential program. Study results indicate that respondents did not feel the current system of support was adequate for planning for their child’s future, nor sufficient for monitoring the quality of life for their children in
the future. Although almost all families had identified a person to support their family members when they were no longer able to do so, parental caregivers overwhelmingly identified the need for the Lifetime Assistance program and many were willing to pay for this service themselves.

KEYWORDS family caregivers, financial planning, futures planning, intellectual and developmental disabilities, quality-of-life monitoring

Many children and adults with disabilities, including those with intellectual and developmental disabilities (IDD), are in need of ongoing formal and informal supports throughout their lives. Parents and family members often act as a primary caregiver and an important advocate for their adult children with IDD (Braddock, 1999; Prouty, Alba, & Lakin, 2008), mental illness (Cook, Cohler, Pickett, & Beeler, 1997; Meeks & Murrell, 1997), HIV/AIDS (Linsk & Pointdexter, 2000), and physical disabilities (Cristan, 2006). One of the greatest concerns among parental caregivers supporting their children with IDD is identifying who will fill their important caregiving, advocacy, and support roles when they are no longer able to do so (Hatfield & Lefley, 2000; National PLAN Alliance, 1995; Wikler, Wasow, & Hatfield, 1983). Although a number of programs were developed over the past several decades to help parents and adults with disabilities in planning for the future (Etmanski, 1996; Ohio Department of Aging, 2000; Susa & Clark, 1996), there is still little knowledge about the particular lifelong planning and caregiving needs that parents have and their willingness to pay for future planning and caregiving. This article introduces a new model of future planning designed for parents of children with IDD called Lifetime Assistance, as well as findings from a study examining the future planning needs of parents of children with IDD and the willingness of parents to pay for a service such as Lifetime Assistance.

BACKGROUND

Future life planning is an increasingly important activity for people with disabilities and their families. For people with IDD, the need for such planning has increased as life spans have increased. The average life span of a person in the United States with IDD is now approaching 70 years (Janicki, Dalton, Henderson, & Davidson, 1999; Warren, 1998). Currently about 640,000 adults with IDD older than age 60 live in the United States, and this number will double by the year 2030 (Heller, Janicki, Hammel, & Factor, 2002). More than one half of adults with IDD live in the home of a family member, often in their parental home (Prouty et al., 2008).
Need for Futures Planning

As parental caregivers of adults with disabilities age, they often face the dual strain of their own aging process and the aging of their adult children who will likely outlive them. This is particularly true for parents who have been a primary caregiver and may be unfamiliar with social service system and other community supports (Smith, Fullmer, & Tobin, 1994). Likewise, social support systems may become overwhelmed by the complex needs of families who are entering the system with aging caregivers and adult children with disabilities (Campbell & Herge, 2000).

One stressor for aging parents of adult children with IDD is planning for their adult child’s future, particularly the transfer of care when the parental caregivers die or become unable to care for their adult children. Numerous studies have reported that parents are concerned about a range of issues relating to the future of their adult children with disabilities, including guardianship, transportation, residential living, and potential burdening of siblings (Freedman, Griffiths, Krauss, & Seltzer, 1999; Minnes & Woodford, 2004; G. Smith, 2003). Despite these concerns, many parents do not make long-term plans with their children with disabilities (Heller & Factor, 1991; Kaufman, Adams, & Campbell, 1991; MetLife, 2005; G. Smith, 2003). Lack of planning has been attributed to lack of information, anxiety over hiring a lawyer, or simply the fear and stress related to their own mortality (MetLife, 2005). When parents do plan, they often focus on short-term choices and goals rather than future financial and legal arrangements (M. Smith, 1997). Without earlier planning, adults with IDD may be placed in inappropriate institutional settings, and their new caregivers may not have adequate information about their likes, dislikes, aspirations, unique needs, and abilities.

Models of Futures Planning

With the growing emphasis on future life planning for adults with IDD and their families, several types of future life-planning programs now exist (Etmanski, 2000; Ohio Department of Aging, 2000; Susa & Clark, 1996). Future life planning is geared toward ensuring the quality of life (QOL) for an individual with a disability after his or her caregivers are no longer able to continue their caregiving role (Freedman & Freedman, 1994; Heller, 2000). Frequently identified topics included in a future plan are financial, medical, residential, retirement, recreational, and guardianship planning. Several approaches are used by future life-planning programs to support families, including programs that provide accurate information and support to families, peer support programs for family caregivers, future planning programs specifically geared toward helping people with IDD make retirement decisions, or programs that combine these approaches (Heller & Caldwell, 2006). Although future life-planning programs have proliferated and are
generally appreciated by participants, some of the programs have had limited success in having participants develop and execute future plans (Etmanski, 1996; Preston & Heller, 1996). Some have not included the person with the IDD or his or her siblings in the process (Heller, 2000; Heller, Miller, Ksieh, & Sterns, 2000; Sutton, Sterns, & Schwartz-Park, 1993), whereas others have provided future life-planning training and peer support to adults with IDD but have not included the family in these future planning efforts (Heller, 2000). The future life-planning program with the most positive empirical evidence is The Future is Now: A Future Planning Training Curriculum for Families and their Adult Relatives with Developmental Disabilities. This comprehensive planning program incorporates training and information, peer support for families, and peer support and training for the adult with an IDD and has resulted in many participants completing letters of intent and other planning activities (Heller & Caldwell, 2006).

Although evidence shows that properly designed short-term training and peer support programs can help families and individuals with IDD plan for the future and help to develop some important planning documents, few programs currently provide lifelong assistance. As planning is not a one-time occurrence, but rather an ongoing process (Bigby, 2000; Smith et al., 1994), the short-term approach common to future life-planning programs may not provide families with the lifetime support they really need. Thus, though families indicate a desire for future planning and organizations are beginning to provide such supports, there is still need for more information on the specific type of future planning supports that will be useful for planning and ongoing support over the lifetime.

A new approach that combines future life planning with ongoing planning and caregiving support is the Lifetime Assistance model (Arc Greater Twin Cities [AGT], 2008). Lifetime Assistance provides families and adults with IDD support for planning and monitoring of well-being that can continue after family members are no longer able to be primary advocates. This model combines planning for financial and personal well-being with the use of a paid, designated lifetime assistant called a Quality-of-Life Specialist. Quality-of-Life Specialists help families of people with IDD plan for the future as well as monitor the QOL and financial well-being of an individual when his or her family members are no longer able to provide care. The Quality-of-Life Specialists become substitute advocates that provide much of the same type of monitoring of supports and services that parents or family members provide.

Similar approaches, such as the Planned Lifetime Assistance Network (PLAN), in some states affiliated with the National Alliance on Mental Illness (NAMI), are becoming common for future planning and supports for adults with mental illness. PLAN programs, which are present in 21 states, typically focus on financial planning and development of representative payees for people with lifelong disabilities (National PLAN Alliance, 2007), though some
do monitor services. There has been no comprehensive evaluation of PLAN programs, though findings from a very small, nonrepresentative study point to success in reducing family stress and increasing overall QOL of older people with mental illness (Obloy & Hutchinson, 2002).

As variations of the Lifetime Assistance approach to planning and supporting adults with a variety of types of disabilities and their families are growing, it is useful to know the utility of these services to families. The specific research questions addressed in this needs assessment are

1. Does the current system of case management adequately support individuals and families to plan and prepare for the personal and financial well-being of their family member with a disability?
2. Who do families currently designate to ensure financial stability and QOL for their family member with a disability?
3. What services and supports do families currently provide to their family member with a disability?
4. Are families interested in and willing to pay for lifetime assistance services?

METHOD

A survey informed by focus groups was used to gather data for the current study at Arc Greater Twin Cities (AGT), an advocacy and education organization serving people with IDD and their families in a seven-county metropolitan area. The current study was part of a general needs assessment used by the agency in preparation for developing a future planning program for family caregivers, which it has subsequently implemented.

Focus Groups

To inform the survey development, four 90-minute focus groups were held with 25 participants. Participants were recruited by AGT using selective sampling procedures aimed at gaining participants representative of the overall AGT clientele. Participants represented a broad range of socioeconomic statuses, ranged in age from approximately mid-twenties to seventies, and included males and females. Two morning sessions and two evening sessions were held in two community centers, a local library, and the AGT office. Each focus group included a brief introduction, an overview of the Lifetime Assistance Program, a statement about the purpose of the focus group, pointed questions related to services for individuals with disabilities, and information about the Lifetime Assistance pilot project. The primary questions asked of the focus group participants were (1) In thinking about the future of your family member with a disability, and that you may precede them in death, what do you most want out of this service? What specific
services need to be offered? (2) What do you perceive to be the barriers within the development of the Lifetime Assistance Program? and (3) What should we consider as we plan a fee for a service program that will be accessible to people of different economic levels? Main points from each of the focus groups were recorded on flip charts. These points were discussed among members of the research team to establish primary themes. Themes that emerged from the four focus groups were used to inform the development of the survey instrument.

Survey Instrument

The survey instrument was developed by AGT staff and researchers. Areas of focus for the survey were drawn from previous demonstration programs and studies (Met Life, 2005; Preston & Heller, 1996; Susa & Clark, 1996) as well as the focus group findings. A pilot of the survey was conducted with five families of varied ages who had utilized services from AGT in the past year. The survey was changed based on pilot feedback, which served to provide a measure of face validity and content validity. Additional content validity was added from the focus group results, which illuminated the range of topics that a futures planning program should address. The survey instrument contained a total of 23 response items, several of which had contingency-based follow-up questions. Survey items elicited demographic information as well as opinions on the quality of each respondent’s current supports for monitoring the financial and lifestyle well-being of their family member with a disability, questions about openness to participation in a fee-based lifetime assistance planning program, and general information about the current level of future planning in which the family had engaged.

Survey Participants

The final survey tool was sent to a systematic random sample of families who had received services from AGT in the past year or who were an AGT member. All eligible families were entered into a database in alphabetical order, and the survey was mailed to every fifth family on the list. Surveys were sent in a return-addressed stamped envelope, and a reminder card was sent 2 weeks after the mailing of initial survey. Of the 891 surveys mailed, 244 (26%) were returned. Most respondents were mothers between ages of 41 and 50 (see Table 1). The family member was usually younger than 21, with moderate mental retardation or other developmental disabilities.

Data Analysis

Data obtained from the 244 completed surveys were analyzed using SPSS 16. Survey data were checked for errors and cleaned before descriptive analyses were conducted to identify general trends in the data. A series of standard
chi-square tests were performed to identify differences in association between cross-tabulated variables.

**FINDINGS**

In addressing the proposed research questions, several relevant findings were revealed by the current study related to (1) the adequacy of current services and support for future planning and support of people with IDD in the future, (2) the person(s) designated to look after QOL for the person with IDD in the absence of the parental caregiver, (3) the services and supports families currently provide and those they are willing to pay for in the future, and (4) the need for a Lifetime Assistance Program to support financial and program planning as well as QOL.

**Adequacy of Current Services and Support for Future Planning**

Respondents generally indicated low levels of satisfaction with county case management services related to financial planning and monitoring of QOL.
and services. About 34.7% were dissatisfied or very dissatisfied with their case manager in the monitoring of their child’s current services, suggesting that case management services may be deficient when it comes to service monitoring regarding future planning. Similar numbers were reported regarding the quality-of-life monitoring; 34.1% were satisfied with the services of their case manager and 32% were dissatisfied. In the area of financial planning, 39.4% of respondents indicated that they were dissatisfied with their case manager, compared to only 22.2% who were pleased. Notably, 18% of respondents were “very dissatisfied” with the financial planning that case managers initiated, indicating fairly high levels of frustration in the area of financial preparation. These results suggest the need for alternate forms of future planning, as dissatisfaction with current case management services is high in each of these three areas.

Person Selected for Quality-of-Life Monitoring

The overwhelming majority of respondents (73.9%) reported that they already had someone in place to monitor their family member’s QOL should the respondent no longer be able to do so. As a general trend, older respondents were more likely to report that they had a person in place to monitor the quality of services for the person they supported than were younger respondents, with this trend being most pronounced after age 50, \( \chi^2(4, N=236) = 13.20, p < .01 \). However, even younger families typically reported that they had designated a person to monitor their relative’s QOL.

The vast majority of respondents indicated that, should they become unable to do so, they selected another family member to monitor the QOL of their relative with a disability (see Table 2). Only eight selected a paid professional. Respondents 50 years of age and younger were more likely to select either the other parent or a relative to act as a monitor. Those older than age 50 were most likely to have selected a sibling of the person with a disability.

Current and Future Support Services

The survey asked respondents to indicate which services and supports they currently provide to their family members with a disability and which they

| TABLE 2 Person Selected to Monitor Quality of Life by Caregivers’ Age |
|-------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Caregivers’ age | Sibling | Parent | Relative | Friend | Paid professional |
| ≤40 | 0 | 13 | 12 | 3 | 0 |
| 41–50 | 12 | 23 | 23 | 8 | 1 |
| 51–60 | 31 | 15 | 11 | 9 | 5 |
| 61–70 | 19 | 4 | 3 | 1 | 0 |
| 71+ | 18 | 5 | 0 | 1 | 2 |
| Total | 80 (36.5%) | 60 (27.3%) | 49 (22.3%) | 22 (10%) | 8 (3%) |
were willing to pay for either now or in the future. Responses to these items varied based on survey respondent age, age of the family member with a disability, and the living situation of the family member with a disability (see Table 3). Caregivers said they currently provided a wide range of day-to-day services for their family members, with more than three fourths indicating they are involved in obtaining services, assisting with personal needs, ensuring participation in social activities, providing a stable living environment, providing transportation, and helping maintain family relationships.

Although not always the case, families with younger caregivers, families in which the child with a disability lives in the home, and families with younger children tended to exhibit more willingness to pay for most services than other families. Families were somewhat ambivalent about the prospect of paying someone to provide support services for their family member with a disability if the primary caregiver became unable to do so. In only two categories of support, ensuring family members get needed services (53%) and help with paperwork for maintaining government benefits (50%), did at least one half of respondents indicate a willingness to pay for supports.

Desire for Lifetime Assistance Services

The final focus of the current study was to examine the extent to which families desired financial planning and financial assistance services. A great majority of respondents (81%) indicated that they were interested in having someone help them with financial planning now or in the future. Those that had family members living at home were significantly more likely to be interested in financial planning than those whose family members were living in out-of-home placements (see Table 4). The expressed interest in pursuing financial planning differed based on respondent age, \( \chi^2(8, N=236) = 41.14, p < .001 \), and the age of the family member with a disability, \( \chi^2(6, N=236) = 29.85, p < .001 \). In both cases, younger age suggested a greater willingness to pursue financial planning. Fifty-four percent of families had already completed some forms of financial and legal planning on behalf of their family member with a disability (see Table 5). The yearly amount of money the caregiver was able to pay for the QOL Specialist did not differ by whether the person lived in the home.

Of individuals who responded to the survey item soliciting interest in a paid Quality of Life (QOL) Specialist \((N=216)\), 4.2% reported that they were currently interested in paying for the service, 61.1% stated that they may be interested in paying for such a service in the future, and 34.7% did not have an interest in paying for QOL Specialist services. As with the willingness to pay for financial services, younger caregivers, \( \chi^2(8, N=216) = 18.33, p < .05 \), and caregivers of younger people with disabilities, \( \chi^2(6, N=216) = 29.70, p < .001 \), appear more likely to have willingness to pay for the services of a QOL Specialist either presently or in the future.
TABLE 3 Caregivers’ Willingness to Pay for Supports by Age and Living Situation of Family Member with Disability

<table>
<thead>
<tr>
<th>Supports</th>
<th>Age of family member</th>
<th>Living situation of family member</th>
<th>( \chi^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( \leq 20 )</td>
<td>21–30</td>
<td>31–40</td>
</tr>
<tr>
<td>Ensure family member gets needed services</td>
<td>Yes %</td>
<td>59.9</td>
<td>59.5</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>40.1</td>
<td>40.5</td>
</tr>
<tr>
<td>Complete paperwork to maintain government benefits</td>
<td>Yes %</td>
<td>57.7</td>
<td>51.4</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>42.3</td>
<td>48.6</td>
</tr>
<tr>
<td>Ensure participation in social/leisure activities</td>
<td>Yes %</td>
<td>55.6</td>
<td>56.8</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>44.4</td>
<td>43.2</td>
</tr>
<tr>
<td>Assist with personal needs</td>
<td>Yes %</td>
<td>53.5</td>
<td>40.5</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>46.5</td>
<td>59.5</td>
</tr>
<tr>
<td>Assist in the design of person-centered planning</td>
<td>Yes %</td>
<td>39.4</td>
<td>43.2</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>60.6</td>
<td>56.8</td>
</tr>
<tr>
<td>Assist with bill paying and finances</td>
<td>Yes %</td>
<td>47.2</td>
<td>45.9</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>52.8</td>
<td>54.1</td>
</tr>
<tr>
<td>Troubleshoot issues to avoid crises</td>
<td>Yes %</td>
<td>44.4</td>
<td>45.9</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>55.6</td>
<td>54.1</td>
</tr>
<tr>
<td>Assist in maintaining family relationships</td>
<td>Yes %</td>
<td>39.4</td>
<td>37.8</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>60.6</td>
<td>62.2</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01, ***p < .001.
The current study presents the findings of a needs assessment to determine the feasibility and specific desired elements of a futures planning program for individuals with IDD and their families. The study provides ideas about the importance of futures planning for individuals with IDD and the specific elements of this service that may be of most benefit to various types of families. These findings are useful to social workers and other human service professionals who are in a position to assist people with IDD and their families in planning for the future. The current study demonstrates that parents of children with IDD are generally favorable about a lifetime assistance model with a QOL Specialist for helping with future planning as well as providing ongoing monitoring for QOL issues. This planning approach complements the more time-limited approaches that are more common in the IDD field, including training and information, peer support for caregivers, and support and training for older adults with IDD.

Findings from the current study suggest that younger families may have a tendency to see more need for a Lifetime Assistance Program than do older...

### TABLE 4  Interest in Planning Services for Individuals Living In or Out of the Family Home

<table>
<thead>
<tr>
<th>Relative lives in family home</th>
<th>Interest in financial planning</th>
<th></th>
<th></th>
<th></th>
<th>(\chi^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>In future</td>
<td>No</td>
<td>(\chi^2)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>96 (54.2%)</td>
<td>59 (33.3%)</td>
<td>22 (12.4%)</td>
<td>19.16, (p &lt; .001)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>17 (29.3%)</td>
<td>20 (34.5%)</td>
<td>21 (36.2%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Willing to pay for quality of life specialist</th>
<th></th>
<th></th>
<th></th>
<th>(\chi^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7 (4.3)</td>
<td>110 (67.5)</td>
<td>46 (28.2)</td>
<td>13.24, (p &lt; .001)</td>
</tr>
<tr>
<td>No</td>
<td>1 (1.9%)</td>
<td>22 (42.3%)</td>
<td>29 (55.8%)</td>
<td></td>
</tr>
</tbody>
</table>

### TABLE 5  Financial and Legal Planning in Place

<table>
<thead>
<tr>
<th>Type of planning</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust</td>
<td>14.3</td>
</tr>
<tr>
<td>Supplemental needs trust</td>
<td>32.4</td>
</tr>
<tr>
<td>Will</td>
<td>31.6</td>
</tr>
<tr>
<td>Life insurance</td>
<td>20.9</td>
</tr>
<tr>
<td>Power of attorney</td>
<td>15.6</td>
</tr>
<tr>
<td>Conservatorship of estate</td>
<td>20.9</td>
</tr>
<tr>
<td>Other</td>
<td>4.1</td>
</tr>
</tbody>
</table>

*Note: Total % is >100 because respondents could select more than one category.*
families, perhaps because they have more time to plan, and partially because they most often have not yet established services that incorporate elements of ongoing support, such as residential supports, for their family members with disabilities. Findings also show that younger families exhibited a greater willingness to pay for these services, possibly because their children more often live in the family home, whereas older respondents, who are more likely to have a child living outside of the home, do not need to invest as much energy in monitoring daily services, as these services are covered through residential or vocational programs. These findings imply that effective Lifetime Assistance Programs will need to concentrate on early intervention, beginning the planning process when families and individuals with disabilities are still fairly young, to have the greatest impact. Programs should still be opened to older families as well; however, planners and program administrators should be knowledgeable about the differing needs of families in earlier and later stages of planning and will need to tailor the lifetime assistance services to the specific needs of individual family systems.

A challenge to the long-term sustainability of the model of lifetime assistance planning outlined in the current study is how to make the program accessible to families of all socioeconomic strata. The Lifetime Assistance model incorporates many elements, including a paid QOL Specialist and fee-for-service financial planning and legal services. The cost of such services may be in excess of what many families are able to pay, possibly contributing to the fact that the majority of respondents in this survey expressed interest in a Lifetime Assistance Program but preferred to delay involvement with such a program until a later time. Although a program that operates on a sliding fee scale may be part of a solution to the problem of sustainably and equitable access, the feasibility of launching a highly complex program involving multiple components, such as this Lifetime Assistance model, is questionable, because substantial startup funds are needed to finance the initial implementation of such a detailed program.

Sustainability solutions for futures planning for individuals with IDD and other lifelong conditions may exist at the policy level. For example, making allowances for lifetime planning within the scope of Medicaid waiver services could clear the way for government reimbursement of some services offered through a futures planning program. If such allowances were extended to parents when their family members with IDD were young, the extended planning period could result in financial planning that would reduce the reliance on government-funded services later in the child’s life and would afford more equitable access to high-quality futures planning supports.

In addition, increased training for case managers and other service providers within the traditional service delivery system may be useful in promoting future planning. Although it may be unrealistic to assume that case managers, whose caseloads are often quite large, will be able to accept the
increased workload associated with systematic futures planning, it is possible that counties or states could hire a futures planning specialist to work with families, thus reducing the responsibility on case managers directly. Additionally, it is possible that counties or states could contract such services with private entities such as local advocacy or service delivery organizations. Regardless, the findings of the current study do suggest that service recipients have a relatively high degree of dissatisfaction with futures planning in the current case management system, indicating that improved training mechanisms may be warranted in this area.

The results of the current study are limited by a number of factors, which should be considered in the interpretation of results. First, these findings are based on the results of a needs assessment program that had not yet been implemented. Although this does enable useful interpretation of the service elements that are important to users of a potential futures planning service, it is important to recognize that perceptions may change once families gain experience within the program. There may be variability in participants’ experiences based on a myriad of demographic and other factors. In addition, the study was conducted in one geographic region and related to one agency that was hoping to implement a Lifetime Assistance Program. Variability among different human services agencies that may wish to implement similar programs is expected based on populations served, the availability of lifetime planning resources in the community, and state and local laws that may result in differences in regulations and services pertaining to futures planning. Despite these limitations, the current study presents findings that are of high importance to many families with members with IDD and other lifelong conditions, as well as social workers and other professionals who assist families in future planning.

REFERENCES


