

## Ruth and Ted Braun Fellowship Application

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**Title, First Name, Last Name:** Dorothy Millar, Ph.D.

**Position Held:** Professor, College of Education, Department of Advanced Educational Studies

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**Project Title:** Age of majority: Maximizing autonomy of young adults who have disabilities

**Field of Study:** Special Education

**Project Abstract: (limited to 500 words that includes who, what, where, when and why)**

The importance of developing self-determination attributes in youth with disabilities is emphasized in key legislation (e.g., Individuals with Disabilities Education Improvement Act - IDEIA). In addition, there is a growing body of research that provides evidence that self-determination does positively impact employment outcomes, post-secondary education, and overall quality of life. Despite efforts directed toward increasing self-determination of youth with disabilities such that they can communicate their preferences and advocate for themselves, little is known about how self-determination is being impacted when students reach the age of majority, and become legally responsible for their decisions and actions. When a student reaches the age of majority, IDEIA mandates that all rights accorded to parents are to transfer to students unless the student is determined to be incompetent and considered unable to provide informed consent. When competence is questioned, the issue of guardianship is often raised. It is important that educators and family members know that parents do not automatically remain a guardian of their son or daughter because of a disability, and that only a court can appoint a guardian for someone 18 years of age or older. It is also important to understand that guardianship is not necessary for every individual with a disability and alternatives to guardianship exist. In order to make informed decisions when answering the question as to whether a legal guardian is needed, it is necessary to have knowledge of guardianship and its legal process. It is common practice that standardized IQ and academic performance assessment be used to determine level of competence, however, these assessments do not address functional life skills. Assessments that could help identify functional skills students need to avoid unnecessary guardian appointments, therefore are necessary. Prior to reaching the age of majority, it is possible that the school evaluation process be proactive and identify strengths and weaknesses so that individuals can become and remain self-sufficient adults. Assessment results could help determine what might be worked on while the student is in school to ensure that unnecessary guardianship appointments do not occur. Alternatives to guardianship, specific to the student, could be suggested, implemented, and evaluated to determine their effectiveness and adjusted if needed.

This proposed project involves three interrelated activities: 1) authoring a book intended for educators (public and university levels), families, and agency personnel that addresses self-determination and guardianship process; 2) designing and piloting an assessment to accompany the text; and 3) completing publishable research that would result from project work.

The activities will expand the research I have been involved in for several years. If awarded, I plan to use a portion of the funds to address the need for time—given that the Fellowship would run from January 2011 to December 2013, I request release time from a 4 credit hour course in each of the next six semesters. Additionally, I would not teach during the Spring/Summer- therefore I would like to use some funds to supplement my salary. Remaining funds would go to support piloting participants.

**Submission to the Internal Review Board (if applicable)**  Yes  No (Note: I will submit an RPA when appropriate)

**Start date of project:** January 01, 2011

**End date of Project:** December 31, 2013

### Description of the proposed project and activities

**Background:** As presented in the special education legislation Individuals with Disabilities Education Improvement Act (IDEIA), the purpose of IDEIA is to ensure that all students with disabilities have available to them a free and appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living [602(d)(1)(A)]. Of particular interest is the last part of the purpose statement that acknowledges the importance of the transition process, which in the most basic sense refers to when students change their status from being children to assuming emergent adult roles in the community. The importance of the status change is evident throughout several sections of the IDEIA policy. As an example, IDEIA states that the term “transition services” refers to a coordinated set of activities that: *is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment, continuing and adult education, adult services, independent living or community participation, and is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests [602(34)(B)].* Further, IDEIA specifies that beginning not later than the first Individualized Education Program (IEP) to be in effect when the child turns 16 and then updated annually thereafter, the IEP must include: (a) *appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and independent living skills;* (b) *transition services needed to assist the child in reaching those goals, including courses of study;* and (c) *beginning not later than one year before the child reaches the age of majority under state law, a statement that the child has been informed of the child’s rights under this title, if any, that will transfer to the child on reaching the age of majority under Section 615(m).* In Section 615(m), a special rule regarding procedural safeguards, states that the right of transfer is to occur for all students with disabilities, unless the student is determined incompetent by State law or considered unable to provide informed consent regarding educational programming. For these situations, when student competence is in question, IDEIA mandates that States establish procedures for appointing an individual (e.g., parent) to represent the educational interests of the student [Section 615(m)]. Although the special rule has been mandated for well over a decade, no systematic examination exists regarding the extent to which, or how, States have established these procedures. Upon a cursory inspection of state department of education IEP forms, some States have responded in part by including boxes on the IEP form to indicate that the student had reached the age of majority and that a guardian was appointed by court order; and/or had reached the age of majority and had appointed a legally designated representative (e.g., power-of-attorney, trustee) (Michigan Department of Education-MDE, 2005). Further, in the IEP manual, the following information is presented: *Guardianship issues (e.g., independence, decision-making, partial guardianships as appropriate) can be addressed in the student’s secondary education career in the IEP under Transition services (e.g., Courses of study, Adult living, Daily living)* (MDE, Section 1-2, 2005). Although some State supported IEP manuals suggest that guardianship-related issues be discussed, statements such as this may be interpreted that guardian appointments are needed (Millar & Renzaglia, 2002). This perceived need is of concern because it is has been learned that some parents and educators do not have complete or accurate information regarding the legal process (Millar, 2007). Briefly, guardianship is the process by which an individual (a petitioner) requests that a court appoint someone (a guardian) to have the power to make decisions for, and handle the affairs of, another (a ward). Depending on the court’s ruling, wards may (unnecessarily) lose all legal and civil rights (Millar, 2003).

**Research to Date:** For hundreds of years, guardianship has existed, however, limited research exists regarding how it impacts the lives of individuals involved (e.g., ward, petitioner, guardian). When considering IDEIA, and the impact guardian appointments may or may not have on the rights of school-aged individuals, research is even more sparse. It has been recognized by scholars in the field that I have been first to conduct and publish studies on this topic. My first two studies (Millar, 2003; Millar &

## Ruth and Ted Braun Fellowship Application

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Renzaglia, 2002) involved a review of guardianship court files of young adults with disabilities who had legal guardians appointed where it was learned that court petitions were most often completed by parents who claimed that their adult children needed a guardian because the student had a disability, reached the age of majority, and/or had limited to no ability to make sound decisions. Additional findings included that evidence (assessment results) used to determine competence was unclear, but predominately standardized academically focused assessments were used, and that the majority of guardians found their wards' "conditions" of "having limited or no capacity to make decisions" remained unchanged following guardian appointments. This last finding is noteworthy because, as reported in the Mental Health Code Act 258 of 1974 mandates found in the Michigan Compiled Laws Annotated (MCLA), guardians are to assist the ward in the development of maximum self-reliance and independence (MCLA, 330.1602; 330.1631). Using qualitative methods, I further investigated this area and conducted two related studies, both partially supported by SVSU unit grants (Millar, 2008; Millar, 2007). One study involved the facilitation of focus groups where young adults with disabilities (both who had legal guardians and who did not), their parents, and secondary teachers were questioned about their knowledge of self-determination, as well as, guardianship and its alternatives. Two main common findings across groups were that participants had limited understanding of the guardianship process and that they did not realize the extent to which guardianship contradicted their efforts to promote/exhibit self-determination related skills. It was also found that students and parents first learned about guardianship at an IEP when a meeting member (usually a teacher) asked "Do you have a guardian?" when it came to that section on the IEP form. Following the IEP meeting, several parents went to court because they thought becoming their child's legal guardian was something they were expected to do, even though they did not have a clear understanding of what guardian appointments entailed (Millar, 2007). In a related study, using case studies, I explored how two families, with young adults with similar educational experiences and special education school labels, came to very different conclusions about guardianship after they attended an IEP meeting when it was time for the parents' rights to potentially transfer to their adult child (Millar, 2008). One student had a legal guardian and one did not. Interestingly, it was learned that the young man who went through the court process and had a full (plenary) legal guardian appointment made several decisions at his residence and place of employment; whereas the other student who did not have legal guardian had limited control over day-to-day decisions. Actions, values, and beliefs of others (e.g., parents, educators, service providers) impacted the extent to which the young men controlled aspects of their life. Most recently, as a result of some of my sabbatical work, I published the first research article (Millar, 2009) that systematically compared de-identified IEP content of adult students who had or did not have a legal guardian across the following areas: (a) post-secondary goals related to training, education, employment, and independent living; (b) transition services used to meet those goals including course of study, review of objectives, and agency connections; and (c) student participation in educational planning. It was found that students with guardians were more likely to earn a certificate of completion, and wanted to remain living with their families, in comparison to students without guardians who were more likely to earn a diploma, and wanted to live on their own. Differences regarding emphasis of objectives related to employment, transportation and self-care were observed. In addition, differences were observed regarding teaching self-determination related skills; students without guardians had more objectives than those with. While obtaining district support of the studies, it was learned that some districts have a policy to have court issued documents in students' files, whereas others do not as school personnel take the parent's word that a student has a legal guardian. It is imperative that all schools have a policy that court orders be placed in student files. In the documents, the rights of the guardian and term limit of the guardianship must be known so that IEP content and education can address the areas of concern. If documents are not accessible, it is possible that schools will allow guardians to have more 'control' than that actually ordered by the court. As an example, it is possible that a limited guardian has the authority to only make medical and dental decisions. If the school does not know this, however, then the schools may assume that all rights of the student have been restricted.

## Ruth and Ted Braun Fellowship Application

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**Proposed Project:** This proposal for the Braun Fellowship seeks support to continue and expand my own on-going research in area of promoting the self-determination of youth and young adults with disabilities. Briefly, the proposed project involves: 1) the writing of a book intended for educators (public and university levels), families (including the individual with a disability), and community agency service providers; 2) the design, implementation, and piloting of a self-sufficiency assessment and activities (to be published with the book); and 3) completion of at least 1 primary research article that is a result of the work conducted in the book, assessment and activities development. In the proposal below, I briefly detail the initial focus of the products, please note however, that I have done a significant amount of groundwork in the targeted area and have produced a number of articles (previously referenced) in respected journals including *Exceptional Children* and *Education and Training in Developmental Disabilities*, as well as presentations in juried conferences *Council for Exceptional Children Expo*, *Division on Career Development and Transition Conference*, and *International Association of Special Education (IASE) Conference*. During my sabbatical, I also worked on drafting some parts of the book outlined below. The information shared in articles and presentations have already been well received by families, educators and scholars; I have similar expectations for my proposed work.

**Book Composition:** For several years, I have considered authoring a book compiling the results of my research. Throughout the winter semester, I will further outline and begin writing sections of the book. The book, assessments, and activities are being designed for youth and young adults with disabilities, in collaboration with family members, educators, and agency service providers (e.g., rehabilitation counselors, mental health case managers). Although I have been at the cutting edge of this area, I will need time to prepare to write the book, as well as conduct a literature review in the areas of guardianship, self-determination, and transition services to ensure I have the most up to date information. I will also need to review the legislation (e.g., IDEIA) and related documents (e.g., Individualized Education Programs – IEPs forms, safeguard procedures). Tentative book contents include:

- Self-Determination - What is it? And Why is it important?
- Rights and Responsibilities under Key Legislation
  - IDEIA, ADA, Rehab Act - Transition Services: It is the law
  - The IEP and SOP – Individualized Education Program and Summary of Performance  
*Note on SOP:* Although the legislation is vague, this document has the potential to serve many purposes as it could include information regarding the extent to which the student possess self-determination skills, where support is needed, and what guardianship alternatives are effective.
  - Age of Majority – Transfer of Rights - Competence and Informed Consent
- Understanding the legal Guardianship process as it Relates to Adults with Disabilities–
  - definition of guardianship, review of the legal process, types and scopes of guardian appointments, types of duties and responsibilities of a guardian, procedures for discharge or modification of a guardian
- Understanding Guardianship Alternatives - Weighing the advantages and disadvantages?
- Assessing Self-determination skills and identifying needs/support to maintain autonomy
- Bringing assessment results into the curriculum
- Collaboration: Agencies, families, educators
- Glossary of Terms, Sample Forms, Case Studies

**Assessment and Activities Design and Refinement:** Based on my research findings, I have advocated that the evaluation procedures used to determine whether someone was in need of a legal guardian be revised. Presently, standardized IQ and academic performance are mainly used to determine ability – both for school placement and guardianship appointments. These assessments do not address functional life skills (e.g., working, recreating, budgeting, health care) which are key aspects of assuming adult roles. As a result, I will make an assessment that could be used to help identify what skills a student needs to avoid unnecessary guardian appointments. That is, prior to the student reaching the age of majority, the school evaluation process can be proactive and specifically discuss the strengths and weaknesses of a student

## Ruth and Ted Braun Fellowship Application

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with regard to that individual becoming a self-sufficient adult. Assessment results could inform the IEP team as to what should be worked on to ensure that unnecessary guardianship appointments do not occur. Least restrictive alternatives to guardianship that are specific to the student should be suggested based on assessment results. The alternatives could be implemented and evaluated to determine their effectiveness and adjusted if needed. In order to create a practical assessment that supplements the text, I will review the current adult-life assessments that have been created, then prepare the assessment and associated activities for publication by piloting them to ensure that they are valid, in addition to being user-friendly. Piloting will occur with practicing educators (specifically those who are students in SVSU special education-related courses), family members, and students. Prior to each fall semester, the piloting teams will be asked to use and critique aspects of the book content, the assessment, and activities. I will systematically track suggested adaptations and any improvement-related observations. I will also collect completed assessments and activity sheets to evaluate whether more complete or in-depth responses could be elicited by refining the language on the items. I plan to include completed samples based on case studies obtained in the piloting phase. If it is determined at any time during this project that this assessment or other activities (e.g., case studies) need to be empirically validated, I will request IRB approval. Examples of assessment content include: (a) *Work and Education: What kinds of jobs have you had? (for pay or volunteer); What kind of job would you like in the future?; What kind of training or education will you need, if any?, and (b) Living 'On your own': Where do you want to live after high-school?; Would you need help with budgeting?; What meals would you have? Where would you buy your groceries?* The student, parent/family members, and educators would each assess the student per skill and discrepancies among the views would be compared in order to determine IEP and curriculum goals. The content of the book, assessment, and activities will be based on feedback from young adults with disabilities, educators, family members, and agency personnel teachers. Again, the main purpose of the book, assessment and activities is to assist students as they make the transition from 'childhood' to 'adulthood'. With a constant focus on self-determination, the ultimate goal of this project is to help students assume responsibility for important life decisions with support from teachers and parents, without unnecessary guardianship appointments.

### **Description of benefits to faculty, community, and the University**

**Benefits to Faculty:** The work completed will undoubtedly benefit my continued development and contributions to SVSU as an educator. I regularly teach a number of upper-division courses where the subject matter of the proposal will be of great benefit. All special education courses will have an appropriate level of the project information presented to students (e.g., survey at introductory level, and in-depth in teacher consultation courses) as I plan to share the information with colleagues. In addition, the information will also benefit the three online transition related courses I recently developed: (a) *TE/ETD 630 - Effective Transition Planning:* Emphasis is placed on using transition-related assessments, using strategies that promote student self-determination, and facilitating family involvement; (b) *TE/ETD 631 - Career and Postsecondary Preparation:* Theory and research-based practices are emphasized that relate to the infusion of career development into academic curricula; facilitation of business relationships; facilitation of consumer-directed job development and placement; and (c) *TE/ETD 632 - Organizational And Community Systems:* This course provides essential information regarding school and community services/systems that impact the education and transition from school to adult living of learners who have special needs. These courses were developed based on the result from a needs/interest survey I conducted in 2008 with teachers and administrators. It is possible that faculty in social work and occupational therapy may also want to use some information that has resulted from this project. **Benefits to**

**Community:** It is anticipated that this project will positively impact the lives of young adults with disabilities, their families and educators as the products will provide needed information as students with disabilities assume adult roles. In addition to those involved in the piloting of materials, those who connect with the following website will have access to some aspects of the information:

<http://www.svsu.edu/typo/index.php?id=7310>. This SVSU website was created, and will be maintained (using support not associated with this project) such that educators, community members, in addition to

## Ruth and Ted Braun Fellowship Application

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families and individuals with disabilities themselves can have access to disability related information. This website is part of a center in the process of being re-established. (Activities were on hold during the past year and a half as I focused my attention on NCATE efforts). The *mission* of the *Center of Ingenuity and Discovery through Education, Alliances, and Scholarship – C of IDEAS* is to enhance the quality of life, across the life span, of individuals with disabilities and their family members by providing leadership and promoting alliances through interdisciplinary training and education, disseminating information pertaining to state of the art practices, and conducting research and program evaluations. The center is comprised of an interdisciplinary, collaborative partnership among individuals with disabilities, family members, educators, community organizations, area businesses, institutions of higher education, and other stakeholders. **Benefits to the University:** As an active member the SVSU community, I anticipate that this project will aid the special education and disability related programs in maintaining its status as a leader in supporting progressive practices in teaching and educational reform. It is hoped that in addition to the COE programs others (e.g., social work and occupational therapy) will find the information of use. Practices advocated in the book are in tune with the reforms and legislation that span across diverse disciplines. Another potential benefit is that by having published authors, there will be an increase regarding the status of the College of Education and the university. Finally, this project will involve educators, families, and community agency personnel as materials and content of the book are created and refined. Word of mouth is a powerful vehicle... their involvement may serve to expand the SVSU's, particularly the COE's, reputation in the area that we are leaders in innovative practice.

**Description of the professional or academic work for publication or presentation:** As previously shared, this proposal seeks support to continue and expand my own on-going research in area of promoting the self-determination of youth and young adults with disabilities. Given the nature of the project—and given my previous work—I expect to publish the book with a publisher that addresses disability-related works (such as Brookes, Merrill/Prentice, or Pro-Ed) with the aim of having IHEs adopt the text in relevant courses, as well as have a publication in a journal well-suited for such work (e.g., *Exceptional Children*) make presentations at international and/or national conferences (e.g., *Council for Exceptional Children, TED, TASH, DCDT*).

**Description of last 5 years of teaching, research, and service demonstrating past performance and contributions:** As found by reviewing my vitae, I have been active in, and successful with, publishing and presenting my research, particularly in the area of transition and guardianship. In terms of service, I have played a key role in the College of Education NCATE efforts. I have also designed and implemented several courses and created new programs (MDE Cognitive Impairment and Revised Autism Applications). I continue to assist with IRB, NCATE reviewer, and departmental work. As far as teaching, I continue to receive strong course evaluation scores from students. Evidence of my work and commitment to the three areas (teaching, research, and service) are verified by my promotion to full professor, being awarded a sabbatical, and receiving nominations for various awards.

**Budget supporting project proposal:** Presently, I teach only graduate level courses. In order to better focus on project work, I am requesting funding for release from one course per Fall and Winter semester, beginning in Winter 2011 (see below for details). The cost to pay an adjunct approximates \$2,000.00. I am also requesting funding to pay for project work for three spring/summer sessions (see below for details). In order to ensure that the products I create are user-friendly and valid, I would like to reimburse the piloting participants. Specifically, the participants would include: 38 piloting participants (10 students with a developmental disability at least 16 year for age, 10 parents/family members of said students, 10 teachers, 4 agency personnel, and 4 administrators). It is anticipated that due to my strong connections with school personnel across several districts, I will be able to have the desired participants in place fairly quickly. Hopefully, these 38 participants will be the same across the three years of piloting, such that I can monitor the progress/changes of students in relation to assessment results. I am also requesting funding to pay for copies of the assessments and activities I will use during the piloting phases.

## Ruth and Ted Braun Fellowship Application

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### Budget Supporting Project Proposal

<b>Year 1 - 2011:</b> 1 (4 cr.) course release during fall & winter semesters: est. \$2,000/adjunct/sem	\$4,000
38 piloting participants (10 students, 10 parents/family members, 10 teachers, 4 agency personnel, 4 administrators) - \$25 per participant	\$950
Printing the assessment and activities	\$300
Spring or Summer semester salary includes FICA and retirement	~\$7,250
<b>Year 1 Total</b>	<b>\$12,500</b>
<b>Year 2 – 2012:</b> 1 course release (4 cr.) during fall and winter semesters: est. \$2,000/adjunct/sem	\$4,000
38 piloting participants (10 students, 10 parents/family members, 10 teachers, 4 agency personnel, 4 administrators) - \$25 per participant	\$950
Printing the assessment and activities	\$300
Spring or Summer semester salary includes FICA and retirement	~\$7,250
<b>Year 2 Total</b>	<b>\$12,500</b>
<b>Year 3 – 2013:</b> 1 course release (4 cr.) during fall and winter semesters: est. \$2,000/adjunct/sem	\$4,000
38 piloting participants (10 students, 10 parents/family members, 10 teachers, 4 agency personnel, 4 administrators) - \$25 per participant	\$950
Printing the assessment and activities	\$300
Spring or Summer semester salary includes FICA and retirement	~\$7,250
<b>Year 3 Total</b>	<b>\$12,500</b>
<b>Project Total</b>	<b>\$37,500</b>