Choice and Control Over Resources: New Hampshire’s Individual Career Account Demonstration Projects

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The Individual Career Account was created as a grant-funded demonstration project in New Hampshire to develop a mechanism for greater individual choice and control over vocational service planning and services. The components of the demonstration included person-centered planning, individualized budgeting, and benefits counseling. This article describes these components and offers individual examples of their utilization by persons with psychiatric disabilities seeking to enter employment. Participant perspectives on choice and control and implications for the design of disability services are discussed.

Part of the shift in society’s response to disability from institutional care toward community inclusion has included an increasing emphasis on individual choice, empowerment, and self-determination (Hagner & Marrone, 1995; Silverstein, 2000; Wolf-Branigan, Daeschlein, Cardinal & Twiss, 2000). Wehmeyer (2002) conceptualized implementation of self-determination as occurring on two levels. At the individual level, it is necessary to define and assess self-determined behavior and develop instructional and other interventions to increase self-determined behavior. At the political or systemic level, change is required to reform agency control over dollars and funding streams in order to enable individuals to implement their decisions and support individual control.

Several specific reforms have been proposed to operationalize these concepts. One important focus concerns developing new personal planning structures that give individuals with disabilities increased opportunities to develop expansive personal goals and aspirations. Traditional service planning has been criticized for remaining heavily dominated by professional choices (Cooney, 2002; Menchetti & Garcia, 2003), restricting plans to currently available agency services (Thoma, Rogan & Baker, 2001), and for often viewing self-determined choices as a “privilege” to be earned through compliance with programming (Cook & Jonkas, 2002).

Person-centered planning has emerged as a promising tool for facilitating increased levels of self-determined choice (Wehmeyer, 2002). Person-centered planning is a facilitative approach used to guide individuals through a series of structured planning sessions designed to help clarify desired outcomes, discover capacities and possibilities for natural supports, and identify reasonable and progressive actions needed to achieve identified goals (Mount, 1992; Pearch, O’Brien & Forrest, 1993). Person-centered planning has been useful in assisting individuals with disabilities to experience more control of the planning process and in achieving career outcomes more consistent with their preferences (Menchetti & Garcia, 2003). As an inductive, qualitative process, person-centered planning explores subjective interpretations and personal meanings in a way that helps establish the individual as the “owner” of his or her plan (Okocha, 1998). In addition, the use of significant others as supports for brainstorming and plan development that is one of the key components of person-centered planning has been associated with enhancing informed choice for individuals who require assistance with decision-making (Hagen-Foley, Rosenthal, & Thomas, 2003). Person-centered planning is also a flexible process that can be used for ongoing planning as circumstances and interests change. A demonstration of an employment choice model in a rehabilitation agency (Wolf-Branigan, Daeschlein, Cardinal & Twiss, 2000) reported high levels of consumer satisfaction with person-centered planning.

Another key component in shifting the focus of planning from agencies and systems to the individual is a reconceptualization of the role of the service coordinator or case manager. Coffey (2003) and Williams and Swartz (1998) noted that the multiple and complex roles of traditional frequently introduce dynamics of
case manager power and control over individuals. Turnbull and Turnbull (2001) and Blumberg, Ferguson and Ferguson (2000) recommended that case management be replaced by a role they call "independent service brokerage" with no organizational or systems allegiances. Demonstrations of independent service brokerage, primarily in relation to individuals with developmental disabilities, have to date been sporadic and informal (Smith, 2003). Wolf-Branigan, Daeschlein, Cardinal and Twiss (2000) designed a choice demonstration project that featured "employment advisors" who were directly employed by consumers. Consumers reported the highest level of satisfaction with this component of the project.

A systems reform critical to offering consumers a greater degree of choice and control is the ability of funding stream to "follow the person" in an individualized manner (Shumway, 1999). Cook and Jonikas (2002) have noted that a comprehensive effort to increase consumer choice and self-determination must consider the possibility that fundamental reform of funding mechanisms is needed. One mechanism that has been proposed is the use of "vouchers" that can be used by consumers to purchase goods and services specified in an employment or habilitation plan (Bertsch, 1992; Steuerle, Ooms, Peterson & Reischauer, 2000). Although there are difficult logistical issues that would need to be resolved in implementing such a proposal, Thomas and Strausser (1995) concluded that the use of voucher systems in a rehabilitation context is an idea that deserves careful investigation.

A final important element of a system that empowers consumers to pursue self-determined goals is the provision of reliable information and assistance about the impact of earned income on public benefits. Many individuals with disabilities depend on benefit programs such as SSDI, SSI, Medicare, Medicaid, housing subsidies and state supplement programs. The eligibility rules for these programs are based on an inability to work, thereby creating a confusing message for those who want to attempt employment. The confusing and inconsistent regulations and requirements of these programs can prevent individuals who depend on them from making and implementing career plans (United States General Accounting Office, 1996).

Many public benefit programs offer "work incentives" provisions which are designed to allow individuals to work and gradually decrease their reliance on public benefits. During the past 20 years, a set of strategies known as benefits counseling has been developed to help individuals utilize these provisions (Golden, O'Mara, Ferrell & Sheldon, 2000). Recent research indicates that benefits counseling can have a significant positive impact on the employment outcomes of SSDI beneficiaries and SSI recipients (Tremblay, Smith, Xie, & Drake, 2004).

The Individual Career Account (ICA) project was established in New Hampshire as part of a State Partnership Initiative funded by the Social Security Administration called Project Dollars and Sense. The project developed an alternative to traditional power relationships and funding mechanisms. This article will describe the elements of the ICA process, and provide examples to illustrate utilization of each element and participant perspectives on choice and control using this model.

**Project Design**

The ICA demonstration was proposed as a demonstration of an employment "voucher" that could be used by adults who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to purchase employment services. A project design committee included stakeholders from the State vocational rehabilitation agency, the mental health center, the mental health peer support agency, and independent living center. The design committee developed referral, intake, and service procedures that was based on the values and principles of self-determination (Research & Training Center on Psychiatric Disability, 2002) and that included three service components: Person-centered planning, individualized budgeting, and benefits counseling. These components were facilitated by a project employee called a Resource Consultant, who assisted participants to develop career goals and identify resources to achieve those goals.

Services were provided to participants in two communities: Manchester and Keene, New Hampshire. One Resource Consultant was assigned to each community. Project staff conducted outreach to the vocational rehabilitation offices, the Social Security Administration field offices, the mental health center, and peer support agencies, in order to reach individuals interested in participating in the project. A total of 89 individuals were enrolled in the demonstration group over a two-year period. Approximately 50% were male and 50% female, with an average age of 43 years. All participants were interested in finding employment or increasing their work hours, and all were SSDI beneficiaries or SSI recipients at the time of enrollment. A substantial majority (83%) had worked before the onset of their disabilities. Most participants (67%) were identified as having psychiatric disabilities. Most (82%) had completed high school or received a General Equivalency Diploma.

Over the course of the project, semi-structured interviews were conducted with a sample of participants, about their perceptions about their vocational situation, their feelings regarding empowerment and control, and their satisfaction with project services. Data from these interview transcriptions are used to illustrate the three service components.

**Person-Centered Planning**

There is evidence that person-centered approaches can have a significant positive impact on the achievement of self-determined employment outcomes (Everson & Zhang, 2000). Hagner, Helm and Butterworth (1996) demonstrated the impact of person-centered planning in facilitating the successful transition of individuals with developmental disabilities in a statewide demonstration project, and person-centered planning has contributed to the achievement of career, postsecondary, and independent living goals for young adults with emotional disabilities in the transition process (Hagner, Cheney & Malloy, 1999).
In the ICA project, Resource Consultants were extensively trained in and utilized facilitation tools from one personal futures planning model, “Methods, Models and Tools” (Cotton, 2003). Facilitation for participants in the ICA project typically included the identification of life and career goals, barriers that require resolution, and resources they may use, including key individuals in their life and involving those individuals in the planning process. Resource Consultants helped individuals break down their vision or dream for the future into manageable parts. As one participant remarked:

It’s helpful, keeping a balance and a sense of focus and coming in to meet with [the Resource Consultant].
And... she charts these little graphs and charts and little drawings....I can reflect back and say, “Geez, I am doing something.” It is being constructive, because then when it’s on paper you can see that “Yes, you have been obtaining goals or working towards the goals.” So, it’s just helping me to be more focused.

Nancy’s career goal was to work full-time as a registered nurse (RN). Nancy had dropped out of nursing school 20 years ago to marry and raise a family. Now that her children were grown, she was ready to again focus on her goal. Nancy knew what she wanted to do, but she wondered if she could handle the stress of schoolwork and assignments. She worried that she would have another depressive episode, and would end up failing her classes or drop out of school if she wasn’t able to manage her major depression. Her mental health case manager and vocational rehabilitation counselor voiced the same concerns.

Nancy’s Resource Consultant met with her at her home each week for several months to help her map out a plan to reach her goal. Becoming an RN involved numerous steps, including applying and being accepted to college, taking the necessary entrance exams, securing financial assistance, soliciting support from her family, purchasing books and supplies, registering for, taking and passing the required courses, completing on-the-job training, passing the state licensing exam, applying, interviewing, and being hired for a job. Each step in turn involved other smaller steps. Nancy and her Resource Consultant also discussed Nancy’s fears about getting sick and failing her classes. Nancy identified supports she would need in place in order to be successful, and identified her warning signs and symptoms of a depressive episode to share with her family and close friends. She asked her family and friends to come and talk to her if they saw warning signs that she was getting depressed, in case she didn’t recognize the signs herself right away. The Resource Consultant documented the planning process and mailed copies of the week-

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Grand Totals:
ly planning notes to Nancy, her case manager, and vocational rehabilitation counselor. By sharing this information with all of the helpers in Nancy’s life, Nancy and her Resource Consultant were able to address their concerns, solicit suggestions, and facilitate discussion. This process acknowledged Nancy’s ownership of her plan while respecting others’ involvement in it.

Individualized Service Budgeting

Individualized funding is frequently mentioned as an important element of a system that seeks to shift the power to choose and control service delivery from agencies to individuals with disabilities. However, there are few existing examples of financial and budgeting structures that make funding accessible and controllable by individuals with disabilities.

The ICA project developed a budget spreadsheet that served as a format to help participants organize their plans and create individualized budgets. This spreadsheet, called the Resource Plan, was used to record a) the participant’s goals in their own words, b) the objectives identified by the participant, c) the items, goods, services and supports needed to achieve each objective, d) the costs, if any, for each item, e) the anticipated funding sources for each good or service, and f) the anticipated provider of each good or service.

Of the 89 individuals who received ICA Resource Consulting services, 45 (50%) completed full individualized budgets. Those who did not complete budgets either did not see a reason to do so, became ill, suspended project participation, or did not reach a point in their planning where a budget was appropriate. A sample Resource Plan for one objective is provided as Figure 1.

ICA participants were encouraged to consider a broad array of provider and funding options when developing their Resource Plans. Budgets frequently included a participant’s own dollars from benefits or employment, as well as “in-kind contributions” from the individual and from natural supports such as relatives, friends, employers and others dedicated to helping them succeed. Participants also worked with the Resource Consultant to ensure that they were using any available work incentives, especially Impairment-Related Work Expenses (IRWE) and Plans for Achieving Self-Support (PASS). Several participants planned to leverage their own funds to secure small loans. This process differs sharply from traditional case management. The Resource Consultant acted solely as the agent of the consumer (Blumberg, Ferguson, & Ferguson, 2000), not a representative of a service or funding agency.

One participant, Marcus, a man in recovery from drug and alcohol addiction, and bipolar disorder and living in temporary housing, wanted to become a certified Microsoft Office User Specialist (MOUS) instructor. He needed financial support to pay for classes, books and other items in order to reach his goal. He identified that he would require ongoing psychotherapy and medication monitoring to maintain his mental health, as well as time to attend AA meetings. Marcus explained his Resource Plan as follows:

Ok, it’s primarily three objectives. They sort of fit together. One is to get the training and the other resources that I need to become employed full time as a master computer trainer. The other one is to get my license back. And get transportation, and buy a car, insurance, all that sort of stuff....
And the other one is to maintain my mental health.

Marcus received tuition assistance from his vocational rehabilitation office, but was denied his request to take one class not required for MOUS certification. Marcus’ Resource Consultant helped him to brainstorm alternative funding sources. He decided to approach the school to propose a bartering arrangement, swapping his services as a teacher for another course in exchange for the course he wanted to take.

Some Resource Plan items required non-monetary resources such as time, effort, or emotional or social investment. For example, Marcus wanted to take a class that was at the same time as his regular AA meeting. Changing to a different meeting meant a greater investment of time to get to the new location, meet new members, and establish a new support network. By including these efforts on his Resource Plan spreadsheet, he was able to document and track his personal commitment and contribution to his goals.

In order to ensure maximum flexibility in the creation of individualized budgets, the ICA project developed agreements in advance with the New Hampshire Bureau of Vocational Rehabilitation and the Division of Behavioral Health, the primary funders of employment services and supports for individuals with disabilities in the state. These agreements allowed automatic approval for service funds (subject only to restrictions against uses of funds that are forbidden by statute) to be used to pay for goods and services on ICA Resource Plans, up to a specified amount, for participants eligible for those funds. The no-questions-asked ceiling was set at the average per-consumer funding amount at the start of the project for each agency. This arrangement resembled a “voucher” system (Bertsch, 1992; Steuerle, Ooms, Peterson & Reischauer, 2000). Additional funds could be requested from these agencies through the usual procedure.

In the process of establishing individualized budget agreements, the project discovered that Medicaid service funds could not be brought under the direct control of service recipients. To remain faithful to the objective of individual control, a special Flexible Career Account fund was established, using grant funds, as an option for participants who would ordinarily have access to Medicaid funding. The project contracted with a special needs trust organization, Enhanced Life Options, to act as fiscal intermediary to manage this account. Such an intermediary has been found to be a helpful component of consumer-directed support (Planagan & Green, 2000; Shumway, 1999). An Oversight Committee comprised of a consumer majority, developed policies and procedures for requesting funds and a process for approving requests over a specified limit. Of the 45 individuals who completed individualized budgets, 22 (48%) developed individual cash accounts using the fiscal intermediary.

For example, Thomas had struggled with the decision to pursue his dream of becoming an artist. He was concerned that he would never be able to succeed financially in this line of work. With the assistance of his Resource Consultant, Thomas researched the costs of supplies and art association memberships and eventually developed a Resource Plan. The plan included a request for $2,400 from the Flexible Career Account fund, granted by the Fiscal Intermediary Oversight Committee. Thomas joined a number of art associations and submitted his work for sale in various shows and galleries. However, soon after, he experienced a family tragedy and he went into a deep depression. For nearly a year, the Resource Consultant kept in touch and encouraged Thomas not to give up. Finally he resumed work on his plan, re-committed to his goal of becoming an artist, and mapped out several new strategies to achieve his goals.

Benefits Counseling

Benefits counseling in the ICA project included (a) an assessment of each participant’s current financial situation, (b) an analysis of the impact of earnings on each participant’s public benefit and overall financial situation, (c) information about the various work incentives available to each participant, and (d) ongoing assistance to participants to maintain and use work incentives over time. Providing individuals with accurate information was considered a critical step in the employment planning process.

Several individuals who were interviewed mentioned that they entered the project largely unaware of how to use work incentives, and under the impression that they would lose needed benefits if they went to work. As one participant commented:

“It’s put my feelings about working in a different light. Before I thought, “OK, I’m on Social Security, I’m on Medicare. I can’t work. (or) I can work but they’re gonna cut me.” And since I've been coming here I found you can work. They encourage you to work.

Lesley, a 50-year-old woman with a degree in criminology and 10 years of experience in law enforcement, had a severe back injury resulting in chronic pain and bi-polar disorder. It had taken her more than a year to be approved for SSDI benefits, and she mistakenly believed she would lose those benefits as soon as she returned to work. Lesley received several hours of benefits counseling from her Resource Consultant, and within 6 months was working as a part-time security officer, earning $693 per month. Daniel, an individual diagnosed with schizophrenia and diabetes mellitus, wanted to go to work but was concerned about losing Medicaid coverage. Daniel had worked at a dozen different jobs since becoming disabled, but each time his earned income would end up going to pay his Medicaid “spend-down” (the amount of Medicaid costs certain individuals who are over-income for Medicaid must pay before reaching eligibility for coverage). Daniel’s Resource Consultant provided information about the state’s Medicaid Buy-In program. It was, in part, the benefits information Daniel received from the Resource Consultant that allowed Daniel to decide to go to work part-time as a janitor, making $10.32 hour, while retaining his Medicaid eligibility. The following statement shows how critical benefits counseling can be to a support model that fosters self-direction and choice:

If I hadn’t came here and we hadn’t talked that day, I never would have gone and looked for work. I would have just sat there and muddled around in my brain and
saying “I can’t do this, because that’s what they told me.” But once we sat down and focused and really talked about everything as a whole and (the Resource Consultant) really explained everything, then I walked out of here with confidence.

Selected Implementation Examples

The project’s Resource Consultants worked with participants on an ongoing basis for up to two years. The combination of person-centered planning, individualized budgeting, and benefits counseling brought together all of the resources available to each participant in the service of personally meaningful career goals. As one participant stated:

You know, it’s just like, ok, this is the system and you know, you have to go with the system but why can’t it be more efficient? And try to help people. I mean, people look at you if you’re in the system like “Oh yeah, you’re just using the system.” No I’m not. I’m using this because I have to, I have to right now.

Of the 89 enrollees in the project, 76 (85%) completed a personal futures plan and were engaged to varying degrees in developing a Resource Plan, and 49 (55%) completed a Resource Plan. Of the 75 enrollees whose primary disability was psychiatric, 33 (44%) had completed a personal futures plan and 26 (35%) had completed a Resource Plan. For most participants, the process of breaking down large goals into small achievable steps and receiving assistance to overcome implementation difficulties allowed them to pursue career paths that they previously experienced as overwhelming and confusing. This section reports several selected examples of utilization of the ICA approach by individuals with psychiatric disabilities over the life of the project.

Marcus

After several weeks in classes at the school where Marcus had bartered an agreement, his supervisor approached him saying their agreement wasn’t working out: It did not feel right to him to allow Marcus to teach as much as he was without paying him. Marcus then began to earn $800 a month in addition to his free tuition and free use of any books owned by the school. This arrangement saved Marcus more than $4,000 in tuition and books he would have paid for the program he was enrolled in.

Marcus’ sense of security has increased, and he has begun to make friends with some of the other teachers and employees at the school. One of the teachers offered to tutor him for free, saving him another $1,200 (at $25 an hour). When his supervisor learned that Marcus was looking for an apartment to rent, he told Marcus about an apartment that would soon be available in a friend’s building, one block from the school. With help from family and friends, Marcus has furnished his apartment and settled in.

In order to restore his revoked driver’s license, Marcus was required to request a hearing, secure letters of support, pay a reinstatement fee, insure his license, get new eyeglasses, and be on probation for one year. Marcus used his money from work to pay the reinstatement fee and insure his license. He received assistance from the Flexible Career Account for his eye exam and new eyeglasses. Finally Marcus received his driver’s license, and was given a used car by a co-worker. The car required $500 in repairs to pass inspection. He used Flexible Career Account funds for these repairs.

Marcus has learned to effectively manage his bipolar disorder and has established a relationship with a psychiatrist he trusts. He recognizes his warning signs and alerts his doctor before he experiences a full-fledged manic or depressive episode. He has missed only one day of work in the past year. As Marcus said in his semi-structured interview:

I’m not just a case number, not just trying to fit me in. All those agencies try to fit you in one little box. And if you don’t fit in that, then they don’t know what to do…. I want to be re-trained but I really don’t know what I want to do…. They say, “Well, here’s a list, pick one.” But that doesn’t help me figure out what I want to do…. And I’ve been teaching. I have a Master’s degree in education…Why don’t they see what I already have? See, Dollars and Sense, by finding out what I already had, was more able to help me figure out a path that would help me utilize the tools and skills that I already had.

Upon completion of MOUS certification, Marcus intends to increase his hours to full-time, use up the remainder of his Social Security Disability Insurance Trial Work Period, and go off of his cash benefits. Marcus received a Social Security Administration Ticket to Work and Self-Sufficiency, and, with the benefits counseling he received from his Resource Consultant, he used the Ticket and the new Expedited Reinstatement work incentive provisions. He assigned his Ticket to an employment network provider who agreed to split the payment of the dollar value of the Ticket with him when his benefit payments are discontinued.

Daniel

Daniel’s goal was to have a steady part-time job with a low stress level so that he could feel productive but continue to focus on maintaining his health. Daniel obtained a part-time position as a janitor and retained his Medicaid coverage through the state Medicaid Buy-In program. Daniel established a savings account for his earned income, and saved enough money to put a down payment on a home, supplemented by financial assistance from a specialized low-income housing finance program. He has moved out of his apartment and into his own home and has been working at the same job for more than a year and a half.

Nancy

Nancy used Flexible Career Account funds to pay for the nursing program she wished to attend, her nursing placement test and application, and two course electives. At this point, she was accepted into the nursing program and was awarded Pell grants and student loans. She used vocational rehabilitation funds to pay for some of her books, supplies and transportation expenses, contributing additional funds from her wages working part-time as a
tutor. She is succeeding in her program and expects to finish her schooling and seek full-time employment in the nursing field.

Thomas

Thomas has received awards for his artwork, been asked to jury an art show (for which he was paid), sold several pieces of art, hosted an open gallery, and was commissioned by two local businesses to create original artwork. However, the lag time between creating and selling a painting remains a problem. Thomas continues to worry about how to make enough money on a consistent basis. He still paints and is connected to the art community, but he shifted his focus for generating earned income to developing his own slipcover business. Thomas was familiar with textiles and frequently incorporated fabric into his artwork, and he is currently writing a PASS to set up a slipcover business. He has already been commissioned for several jobs.

Conclusion

The ICA process, consisting of interconnected intensive and ongoing personal futures planning, individualized service budgeting, and benefits counseling was designed to increase individual control over life goals and the supports needed to achieve them. At the individual level, with assistance from an independent Resource Consultant, participants define goals, research options, examine preferences, and map priorities. These resulted in plans of action that included identification of funding options and self-determined selection of service providers. At the systems level, the flexibility of funding streams was increased to allow individuals to identify specific dollar amounts available for use in their individualized budgets.

This report provides initial information about the rationale for and design of process, and some examples of its implementation for a small sample of individuals with psychiatric disabilities. Subsequent reports will analyze the impact of the ICA demonstration on career and other life outcomes across a range of disabilities.

The differences between the independent brokerage offered by Resource Consultants and traditional case management were evident in the experiences of ICA project participants. For example, Nancy's mental health case manager and vocational rehabilitation counselor were reluctant to help her pursue her desire to work as a nurse. In traditional case management, the conflicting agendas involved in being an employee of an agency providing other services, and the power differential inherent in having control over finances, can sometimes compromise the function of serving as an advocate for the individual (Anthony, Cohen, Farkus, & Cobe. 2000; Williams & Swartz, 1998). In the ICA project, however, Nancy's Resource Consultant answered only to Nancy, and was therefore concerned only with how Nancy could best work toward her personal goals.

Individuals who developed person-centered plans and individualized budgets reported that they were better able to self-advocate and receive support from social service and vocational agencies. As one participant explained:

That's how I worked out the deal with getting the training to work. Actually it's made the process with Voc. Rehab. seamless, 'cause if you're gonna use them efficiently, unfortunately you have to go in there already knowing what you want to do. My experience has been that they expect you to know exactly what you're gonna do and exactly what you're gonna need in order to do that when you walk in the door. And I would guess that in most cases that's not reality.

The role of participant in the ICA project was far more active and self-directed than that experienced by a recipient of traditional services. The self-directed process was lengthy and difficult for some individuals, and several participants stopped engaging at different points in the process. How to best engage and maintain involvement for consumers with a wide range of disabilities should be an important focus for future inquiry and refinement of the model.

One important lesson that can be learned from the initial implementation efforts of the ICA project has been that individual control can only be realized to the extent that funding sources themselves are designed in a flexible manner. In the case of Medicaid funded services, for example, flexible access to funds was not possible and grant funds had to substitute for this lack of flexibility. The challenge to policymakers is to design funding systems that allow appropriate flexibility for consumers while meeting statutory and other restrictions.

The ICA demonstration appears to be a promising approach to a support structure that provides increased choice and control of vocational plans and resources. A comprehensive evaluation of consumer outcomes of this approach and an analysis of expenditures and funding amounts in comparison to traditional service delivery designs are important next steps.

References


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