

## **A place-based approach to supporting low-income minority children and their families: Including children with disabilities**

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*A place-based intervention, The Family Support Project, was designed to assist local community based programs in a Mid-Atlantic city of the United States to become more responsive to the needs of low income, minority children and families, and include families of children with disabilities. Informed by a local needs assessment, several goals were established. These included a): increasing awareness of disabilities and services by providing learning opportunity sessions for families and staff, b) addressing attitudinal barriers to inclusion with outreach activities to youth through interactive theater; c) developing in-house local "disability specialists" to offer ongoing leadership and technical expertise for neighborhood based centers, along with developing a local support system and network of technical consultants in order to connect families with broader community and statewide specialized resources. Results of a formative evaluation indicated that the success of the project depended in part upon building partnerships with families and programs within local communities, and extending these partnerships to human service agencies and schools in the broader community and state. Challenges to implementation and lessons learned were discussed.*

Place-based programs can provide important resources for minority children and families in low-income, urban communities where there are often insufficient recreational, prosocial, and educational opportunities available (McLaughlin, Irby, & Langman, 1994). However, local neighborhood based, nonprofit programs for children and youth in low-income urban communities are often challenged in fulfilling their missions to help children and families because of limited funding and resources (Halpern, 1999). Also, their personnel, while highly dedicated, frequently have insufficient training in developmental and educational concerns of children and youth, particularly in regard to children with disabilities (Scholl, Smith, & Davison, 2005). Staff skills in effectively communicating with parents, school, and state agency personnel may be under-developed as well.

Services in low income communities are also disadvantaged by policy makers who view poor communities as having uniformly the same needs and problems. Such generalizations contribute to the marginalization of families in poverty. Policy makers look for unitary solutions with

undifferentiated services (Tropman, 1998). Poor minority communities, however, are typically quite diverse, with families having complex, multiple needs as well as numerous strengths. Within one city, some neighborhoods are devastated by drug trafficking, while in adjacent neighborhoods, pastors of storefront churches continue to provide outreach and services to the community, and local leaders commit their energies to keep afloat youth development activities and a sense of community (McLaughlin, Irby, & Langman, 1994; Unger, Cuevas, & Woolfolk, 2007). In a study of low income African American families, Burton and Clark (2005) describe the high value that many mothers place on having an attachment to place. These mothers tended to live in the same neighborhoods in which they grew up and had extended family. Their sense of cultural identity and self-esteem were in part intertwined with their "homeplace" (Burton & Clark, 2005). Service delivery approaches are needed that reflect the unique conditions of each neighborhood and their residents rather than "a one-size-fits-all cookie cutter approach" (Mulroy, 2000, p. 38).

While policies of state-level public agencies are typically not structured to focus

upon the welfare of any particular local community, place-based programs can be dedicated to improving a specific neighborhood. Such local community based programs typically have greater flexibility to respond to changing needs, and they can take on an advocacy role for neighborhood residents (Mulroy, 2000). Minority families are more likely to trust and turn to service providers that have had a clear long term positive presence in their community. In the history of these organizations, residents have witnessed and benefitted from the public commitment to, and mutual respect for, the beliefs, values, and shared vision for equality and empowerment of disadvantaged children and their families.

Place-based interventions are also uniquely positioned to identify and address special needs in a low-income community. An often overlooked need is support for children with disabilities and their families (Turnbull & Ruef, 1997). While parents of children with disabilities face daily, unrelenting stressors associated with caregiving, they typically have few options for accessing support. Instead, parents find themselves marginalized and isolated in their communities (Fox, Vaugh, Wyatte, & Dunloap, 2002). Intentional (e.g., prejudice) and unintentional attitudes (e.g., lack of knowledge and inflexibility), along with inadequate accessibility limit the involvement of children with disabilities in their communities (Pivik, McComas, & LaFlamme, 2002). At the same time, parents of these children want and need quality, accessible support systems near their homes (Park, Turnbull, & Turnbull, 2002; Turnbull & Ruef, 1997).

This article describes a demonstration project that was designed to help families and neighborhood place-based programs in an urban community to meet the needs of all children and youth, including those with and without disabilities. A needs assessment was conducted in a Mid-Atlantic city of the United States and the Family Support Project was developed and implemented in response to the unmet needs of minority children and youth and their families. A pragmatic, formative evaluation informed the implementation of the

project.

### **Needs Assessment**

The unmet needs of children and families were identified through a community needs assessment conducted during 2001-2002. Focused interviews were conducted with Executive Directors of six community centers in the city. Sample questions included: "What services does your program provide? What types of clients do you serve? What kind of outreach efforts, if any, has your agency made to persons with disabilities? Is the agency accessible to persons with disabilities? What types of supports are provided to families? What kinds of training, if any, have you received regarding disabilities?"

Interviews were also completed with representatives from nonprofit human service agencies, the Mayor's office, and state social service and public health agencies (e.g., Developmental Disability Services, Division of Family Services, Division of Aging Services, Part C Birth to Three Services). Examples of questions included: "What keeps underserved families from seeking services? Does your staff have the disability information they need to work with families who have members with disabilities? How can this project assist your agency to serve families more effectively? If we offer training, what training would you like?" Interviews were taped and later transcribed. Comments were reviewed for categories, with the following themes emerging: barriers to accessing services, lack of information and disability awareness, needs and gaps in services, and training for staff. Subcategories were then identified, (e.g., lack of family support, frustration with schools).

In addition, one-session information meetings were held at community centers, head start and day care centers, churches, and boys and girls clubs. Family members were encouraged to attend to learn about family support services and to share their concerns. The sessions were conducted by an African American staff member and included information on how to access services, different approaches for dealing with difficulties with service providers, strategies for partnering with service providers, recognizing children's typical developmental milestones, and potential signs

of developmental delays. During these sessions, parents and family members were asked about the types of problems they were experiencing with parenting and accessing needed services. Notes were recorded after the sessions and then entered into a Filemaker Pro database so the information could be integrated with findings from other sources.

Lastly, the presence of specific needs was inferred and/or summarized from recent prior assessments completed by a local private foundation (DeSantis, 1999), local human services experts (Aghazadian, 2001; Brooks, 2001), a state developmental disabilities council and related agency (Children with Special Needs, 2001; Community Systems and Services, Inc., 1996), Kids Count (2001) supported by the Anne E. Casey Foundation, and a local University researcher (Ratledge, 1999).

One primary finding of the needs assessment was that low-income minority parents lacked the support and information to help them effectively advocate for quality services for their children in their communities and schools. They did not tend to join large community wide or statewide parent or advocacy organizations. Instead, they wanted information and support from persons they knew and that they could trust and/or represented organizations that had trust and respect within their local communities. Historically, for example, many low-income African American parents have expressed concerns about their children being misdiagnosed, provided with inappropriate mental health services, and segregated into special education programs by professionals of the majority, white community (Harry, 1992). The families participating in our needs assessment were looking for culturally competent support provided by persons from their communities, who worked in local community settings, and had a mature understanding of the culture of their communities.

We also found that parents of children with disabilities were especially lacking in local support systems to help them manage the stressors associated with caring for children with disabilities. Children with disabilities and

their families experience a world with many challenges including physical barriers, social exclusion, bullying, and attitudinal barriers such as a lack of awareness or knowledge on the part of "typical" individuals (Pivak, et al., 2002). Parents were unaware of information and resources that could help them advocate in various school and community settings for developmentally appropriate supports and accommodations for their children with disabilities.

Secondly, parents of children with disabilities felt there was inadequate availability of after school programs for their children in their neighborhoods, and of those that did exist, they expressed great frustration and dissatisfaction with the quality of services offered. They believed that after-school program activities close to their homes could provide their children with especially meaningful and needed sources of support. However, existing programs in their local neighborhoods were most often staffed by paraprofessionals, part time employees, and young adults who had limited training. Frequently absent was an understanding of learning disabilities, the educational rights of children, and accommodations that could help children succeed. Lack of information was also evidenced by inaccurate beliefs about disabilities. Many staff thought only of disabilities in terms of physical mobility limitations, or severe mental retardation or illness. Some staff questioned the wisdom of inclusion. Even with both legislative and empirical support for the inclusion of children with disabilities into community based child care programs (Moon, 1994; Moon et al., 1994), many were reluctant. Typical within these local community agencies, staff erroneously believed that inclusion required extensive financial resources and/or numerous staff to provide services to children with disabilities (Scholl, et al., 2005).

A third finding of the local needs assessment was that families of youth with disabilities did not perceive "generic" human service agencies (i.e., nonprofit and state agencies not exclusively serving those with disabilities) as adequately prepared to meet their needs. In fact, these generic human service

agencies were often overwhelmed with the prospect of understanding and working with the service delivery system for children with disabilities because the system was so fragmented and difficult to navigate. For instance, in the Mid-Atlantic state where the project was implemented, services for individuals and family members were offered across three state departments and within eight divisions.

Families also experienced frustration with disability and early intervention programs. These service providers often seemed unfamiliar with the resources available in the local community to address child and family concerns that were not specific to a child's disability (e.g., marital conflict, child mental health, child care availability, housing). Hallam, Rous, and Grove (2005) suggest that provider lack of knowledge of community resources may partially be attributed to the variability in the training and professional backgrounds (e.g., nursing, human services, education) of the diverse workforce that provides services to children with disabilities. Further, there are insufficient training opportunities to facilitate service coordination with local community resources (Harbin et al., 2004).

Based upon our assessment, we concluded that there was a need for local neighborhood place-based support for children, youth, and their parents, with a special emphasis on families of children with disabilities. While there was an existing infrastructure of neighborhood based nonprofit organizations in the city, service providers needed to understand and be equipped to help children with many different types of abilities and disabilities. With adequate training, staff could offer more diversity and choices in programming to meet a wider range of children's needs. Moreover, the staff of such programs could learn how to collaborate with schools and state and community wide social service agencies that had more specialized expertise and resources. This could provide families with greater access to services for children and youth with and without disabilities. Parents would learn effective ways to navigate social service delivery systems

beyond their local communities. Lastly, we concluded that parents, youth, and staff needed assistance understanding the value of inclusion and creating a local community atmosphere that was more accepting and welcoming of children with varying abilities and disabilities. Through inclusion, children and adults without disabilities could learn to value diversity and the strengths that each child brought to a program (Fink, 2000; Peck, Staub, Gallucci, & Schwartz, 2004; Scholl, Dieser, & Davison, 2005). Children with disabilities could also receive benefits of inclusion such as having more peer models, increased social skills, and greater opportunities to develop interests, skills, and friendships (Downing & Eichinger, 2002).

### **Implementing the Family Support Project**

Following the identification of needs in the previous stage, the Family Support Project was subsequently developed and implemented in 2002-2004 with the collaboration of several existing local community-based nonprofit organizations in one city. Community centers were longstanding institutions in their communities. They provided services and programs (e.g., child care; after school care; mentoring; and housing counseling and development) as well as leadership, support and advocacy in a comprehensive approach to enhancing community and economic development. The Family Support Project had three components. First, increased awareness and understanding about disabilities was accomplished through outreach to families, with and without family members with disabilities. After-school and human service staff at the community centers were also included in these disability awareness activities. Second, outreach to youth to increase awareness of disabilities and address attitudinal barriers occurred through an arts and theater project. Third, staff working in community centers in low-income communities were recruited and trained to become "Disability Specialists" for staff, parents, and children in their local communities. In addition, a support network was created between the Disability Specialists and with providers in the broader community in order to connect families and local staff with statewide specialized resources. This project received funding from grants from the U.S.

Administration on Developmental Disabilities, Department of Health and Human Services, and a statewide Developmental Disabilities Council. The components of the project are explained in more detail below.

*Learning Opportunities outreach sessions.*

To reach out to families of youth with and without disabilities, "Learning Opportunity" sessions were held. These Learning Opportunity sessions focused on understanding children with disabilities and their families, as well as supporting and empowering all families. The sessions were designed to increase understanding of disabilities and related family support and developmental issues, along with awareness of community resources available to address youth and family support needs. Through these family sessions, parents' questions, myths, and concerns were addressed. Attendees had opportunities to practice positive vocabulary and behaviors that help to bring dignity and respect to people with disabilities by identifying stereotypes about people with disabilities, rephrasing and updating terms traditionally used to refer to individuals with disabilities, and demonstrating different ways to interact effectively with people who have disabilities.

Learning Opportunity sessions were also held for staff at the nonprofit local, community programs. In addition to the goals included in the family sessions, staff were expected to learn about specific types of disabilities, and to learn ways to help family members prepare themselves to more effectively seek services and to advocate for needed services. An important feature of the implementation of all Learning Opportunity sessions was that they were co-lead with at least one facilitator being a family member with a disability. Parents with family members with a disability were recruited prior to the delivery of the Learning Opportunity Sessions, and received a separate training.

*Interactive youth theatre.*

It was important to reach out to not only parents and staff in the local programs, but also youth who attended the local

community center programs, both children with and without disabilities. An art and theater project was developed as a vehicle for increasing awareness of disabilities and inclusion. Youth with disabilities were recruited from local community programs and a local vocational/technical high school to design and then present the project to other youth.

An interactive theater approach, referred to as Forum Theater (Boal, 1992), was chosen because it encouraged audience members with and without disabilities to become part of the presentation, to build upon the strengths and input of youth, and use concerns identified by the youth to direct the course and outcomes of the project. Forum Theater is a drama method that allows the actors of a production along with the audience to jointly explore unjust issues in their communities and then try to find productive solutions. Skits are created by the actors that address social issues relevant to the target audience (e.g., a child with a disability being bullied by his peers). When members of the audience witness these scenarios, they are able to respond to or invent new ways of playing out that scene. In collaboration with actors, audience members create more just and empowering scenarios. As a result of the project, youth learned what disabilities were, and what it meant to live with specific disabilities. Moreover, issues of inclusion and exclusion were discussed along with how power dynamics affected society and youth. Youth learned communication skills and expressive techniques without having any prior experience in performing arts. Lastly, techniques for mentoring and working with youth and younger children were discussed so that the presenters would have skills to deal with topics as they arose during the course of presentations.

*Disability Specialists and connections to broader community resources.*

Individuals already employed at neighborhood community programs in low-income communities were identified and recruited. They were invited to participate in a Fellowship training program, and then serve as "Disability Specialists" in their local communities. The Fellowship included training to increase their expertise in disabilities, as well as financial compensation so they could allocate

more of their professional time to family and staff outreach, and to assessing child and family needs, providing information, referral and follow-up, and help promote self-advocacy.

The idea of a Disability Specialist is consistent with service delivery approaches where the goal is to link minority members with resources of the majority. In such an approach, persons with labels such as cultural mediators, cultural brokers, and parent-school liaisons have helped connect underserved children and their parents with needed services (Maude, Catlett, Moore, Sanchez, & Thorpe, 2006).

Seven Disability Specialists participated in a weekly Fellowship Training Program over approximately five months. A unique feature of the training was that discussions included a focus on collaborating with families, schools, and agencies in the larger community. Disability Specialists learned about children's rights and opportunities in special education, and to identify techniques that parents could use to enhance collaboration with their children's schools. They also learned to: a) identify and demonstrate strategies to achieve effective collaboration between family members and professionals; b) identify strategies for developing an equal partnership between family members and professionals; c) build understanding of family strengths and needs; d) identify barriers to addressing family needs; e) identify and understand services in the community that were available to address individual and family needs; and f) advocate for appropriate and inclusive services for individuals with and without disabilities within their communities.

The topics of the training sessions included: a) conflict resolution and mediation services with schools and special education services; b) laws and rights under U.S. special education laws; c) developing and understanding a quality individualized educational plan for children; d) alternative methods for assessing competence and educational achievement with children with disabilities; e) laws and rights under U.S. disability and anti-discrimination laws; f)

helping parents and children advocate for themselves; g) common mental health problems of children; h) common mental health problems of parents and adult family members; i) managing children's (and parents') challenging behaviors; j) positive behavioral support; k) learning differences among children and adapting instruction and activities; l) barriers to inclusion and removal of barriers; m) an integrated approach to working with children and their families; n) developing linkages with human service partners/providers; o) transition services for young adults with disabilities; p) assistive technology; q) self-care and lifespan respite care; r) family needs and supports; s) professionalism; and t) graduation/celebration.

An important feature of the Family Support Project was the availability of ongoing technical assistance and mutual support to the Disability Specialists. A member of the intervention team provided on-site consultation and support between training sessions at each of the local community programs. This enhanced Specialists' skills for providing case management, and provided the needed support and encouragement when working with challenging youth and their families. An additional significant feature of the Family Support Project was for the Specialists to build a resource network among themselves through which they received mutual support and peer guidance. Continued, ongoing technical and emotional support after the training was also accomplished through monthly meetings, networking between Disability Specialists, and assistance from the project's staff. Although the Specialists all worked within the same city, they generally stayed within their local communities and had not previously had opportunities to meet and learn from each other.

Another distinctive feature throughout the Disability Specialist training was that representatives and providers from state agencies offering services to families and individuals with disabilities were invited presenters. This offered the Disability Specialists opportunities to meet agency representatives, and to begin establishing themselves as known and legitimate entities to the agencies. These relationships and contacts served as important resources for the Disability

Specialists as they worked with youth and their families and referred them for needed services. It also increased the perceived legitimacy of these "local experts" with the larger state agencies and programs.

### **Evaluating the Family Support Project and Lessons Learned**

A formative program evaluation approach was used to evaluate the Family Support Project. The evaluation focused on providing information that would be helpful in documenting, implementing, and refining the project. A database using Filemaker Pro was developed to track the attendance of family members and staff at Learning Opportunity Sessions, along with their satisfaction with the meetings. Over the course of the project (10/2002-6/2004), 368 family members attended the Learning Opportunity sessions, which lasted an average of 1.97 hours (ranging in length from 1-3 hours). The typical group size was approximately 6.9 participants made up of mostly mothers (83%) and some fathers (17%). The majority of participants were African American (54.3%); others were White (30.7%) and Latino (11.1%) (3.8% of family members declined to identify their race/ethnicity).

When Learning Opportunity sessions were held for staff, the majority of participants were African-American (73.1%). The remainder were either White (20%) or Latino (6.9%). The sessions lasted approximately 1.54 hours, with typically 7.9 staff members attending, who were predominately female (78%). Satisfaction with the Learning Opportunity sessions was evaluated using five questions with a four point Likert-style rating scale (e.g., Was the information presented: (1) a good refresher?... (4) new to me?). These were followed by 6 incomplete sentences requiring open-ended responses (e.g., "I still have questions about..."). Responses were then entered into a Filemaker Pro database. Overall, families (90%) and staff members (83%) were very satisfied with the sessions.

During the Disability Specialist training, a similar Learning Opportunity Evaluation Form was completed to provide feedback on each day's topical presentation. To document the activities of the Disability Specialists, each

Disability Specialist completed Activity Logs during and after they received training. On each Activity Log, Specialists indicated the specific focus of their work from a list provided on the Log. Space was also provided on Activity Logs so narratives could be included about a) activity details, b) next steps, and c) help needed. Responses were entered on a monthly basis in a Filemaker Pro database that was then used to create timely reports on a) individual Disability Specialist's activities, b) monthly totals, c) "next steps" underway by Specialists, and d) any help that Specialists anticipated that they would need to carry out their activities.

The types of activities carried out by Disability Specialists over the course of the Disability Fellowship program included: outreach to individuals with disabilities (24%), follow-up with a child, adult, or family member (18%), support or consultation with staff at the Specialist's center (18%), referrals and follow-up regarding referrals (13%), education/disability awareness with human service providers at other community agencies (10%), caregiver counseling and advocacy (10%), seeking information regarding availability and eligibility information for disability services (7%), and hosting group meetings with families or individuals (2%).

#### *Lessons learned.*

There were several important lessons learned from the formative program evaluation of the Family Support Project that could help others desiring to replicate the project. First, Disability Specialists need to have a pre-established "presence" in their local neighborhoods. Our Specialists were already trusted by many families in their local communities, they embraced being involved in outreach activities with youth and families, and had a passion for helping disenfranchised youth with and without disabilities. By virtue of the project's association with key community people, youth and families felt welcome and able to access services in an atmosphere of credibility and reduced stigmatization.

A second lesson was that management at local community programs must "buy into" the importance of serving and reaching out to children with disabilities. Through numerous

disability awareness discussions, the Executive Directors of the participating community centers came to believe that the inclusion of youth with disabilities fit with their organizations' missions, and saw the benefit to families and their communities of making commitments of agency resources to the Project. When we tried to recruit Directors who did not see the benefits outweighing the costs, they did not agree to participate. Scholl, et al. (2005) similarly noted that managers and supervisors in community centers need to not only see inclusion as "desirable" (p. 60), but important enough to allocate resources for their centers to proactively serve youth with disabilities.

Third, collaboration was critically important. Partnerships were developed between families, community centers, human service and state agencies, and schools. The Fellowship training enhanced the Specialists' knowledge of potential resources as well as improved their competencies for accessing these services. Through these new collaborations, the Disability Specialists could more effectively serve the diverse needs of all families, those with and without children with disabilities.

Fourth, Disability Specialists gained confidence and support as a "team." It should not be assumed that because the Specialists were active and productive members of their local communities, that their support systems were adequate. In fact, they were typically overextended and stressed by the overwhelming nature of need and the absence of resources to meet those needs in their local communities. Consequently, during the trainings, time was always provided for Disability Specialists to get to know each other, receive support and encouragement from their fellow Specialists, and to share information and resources. Disability Specialists became a team with mutual concern for each other.

Fifth, Disability Specialists need sufficient time and flexibility in their work schedules. In order to meet the needs of youth and their families, Disability Specialists engaged in a wide range of activities, in different settings, and during various times

throughout the day that went beyond standard work hours. Their activities as Specialists were only part of their job responsibilities at the community centers. It was a strength that Disability Specialists were already part of their community centers prior to the project. However, this also had its problems because the Specialists had other job demands that spilled over into time that was supposed to be allocated for Disability Specialist activities. Without having adequate time and flexible work schedules, Disability Specialists are at risk for stress and burnout.

Lastly, we learned additional lessons about social change. Our experiences confirmed our assumption that social change interventions need to involve multiple ecological systems (e.g., micro, meso, exo, macros; Garbarino & Kostelny, 1995) in order to bring about lasting change. However, we underestimated the strength of existing power differentials in the communities and service delivery systems, and the corresponding length of time that would be needed to begin to address these disparities (Behrens & Foster-Fishman, 2007). For example, we witnessed the devastating and systemic impact of poverty on children and families living in low income neighborhoods. The accumulation of multiple risks over time had taken a tremendous toll on the availability and provision of quality services in these neighborhoods as compared with services available in higher income communities (Evans, 2004; Park, et al., 2002). Also, the pressures and competition for acquiring funds to *maintain* existing services in local, neighborhood based programs was intense, leaving Executive Directors with cautiousness for beginning and sustaining new programmatic initiatives. Furthermore, the prejudice and discrimination experienced by many persons of color was exacerbated with the co-occurrence of disabilities. Disabilities further marginalized low income individuals of color, limiting their economic, educational, and prosocial opportunities, and decreasing their competitive advantage for these resources (Ali, Faxil, Bywaters, Wallace, & Singh, 2001). These barriers were rather intransigent,



and our expectations for helping families needed to be readjusted and subsequently viewed in the context of a series of successive "small wins" (Weick, 1984).

### Concluding Comments

The Family Support Project was a first step toward improving the well being of minority children and their families. The success of the program depended upon a collaborative approach that worked in synergy with youth, families, and local communities, and the schools and social service agencies in the broader community. The major components of success included: a) active place-based collaboration and problem solving with local community center staff and the families they served, b) talented, motivated, key staff from the local community, c) outreach and education to provide a more inclusive, welcoming environment for all, d) inclusion of family members with individuals with disabilities in training and awareness activities, e) allocation of financial resources so that local community staff could reallocate their time to provide Disability Specialist services, and f) developing linkages with resources beyond the local community.

Over the course of the project, staff, children, and families demonstrated the interest, commitment, and feasibility of implementing this place-based intervention. However, we were less successful in convincing the well-established state and federal level public agencies of the need for tailoring and delivering family support services at a neighborhood level. For example, federal developmental disability policy makers in the United States most recently have adopted a "one stop" centralized state managed service delivery approach with the intent of increasing access to existing services.

Since the completion of our demonstration project, variations of the Family Support Project still continue within the original participating local community centers with a variety of patchwork funding. Research is needed that can contrast and compare the relative effectiveness of such divergent service delivery models as place-based and centralized city-wide and state-level programming for improving the lives of low income, minority

children and their families. Similarly important is a continued focus on participatory formative program evaluation for refining implementation issues. Attention must also be directed toward understanding aspects of social and political systems that are more likely to promote rather than impede the development of culturally competent local neighborhood service delivery strategies.

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