SITE VISIT REVIEW: CLINICAL GENETICS & CHILD DEVELOPMENT CENTER DARTMOUTH MEDICAL SCHOOL

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CHILD DEVELOPMENT CENTER
DARTMOUTH MEDICAL SCHOOL

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I. Background and Overview of Organizational Assessment

Rationale

The Clinical Genetics and Child Development Center has undergone significant changes over the past several years, both in terms of its funding base and mission. Initially funded by the New Hampshire Developmental Disabilities Council in 1971, the program began to grow rapidly in the late 1980s when the budget went from about $480,000 in FY 1987, to almost $1 million in FY 1991. This growth in revenues has been coupled with changes and alterations in the Center's mission that have contributed to the multifaceted character of the current Center and its statewide as well as national status. The Center's program has also been broadened by two significant new designations -- as a participating site in the New Hampshire University Affiliated Program and as the home of the Hood Center for Research on Families and Children with Disabilities.

As in any organization that has undergone rapid change and expansion, the administrative infrastructure of the Center has not kept pace with the burgeoning organization and the permutations in the organization's clinical and research functions. Since 1985, the staff at the Center has gone from only one full-time secretary, one full time physician and three part time professionals to an organization of approximately 15 FTEs. As a result, the formal relationships with the larger college and medical community at Dartmouth that worked well when the Center was smaller are now less responsive given the Center's expanded roles and the demands made on its leadership.

For these reasons, an organizational assessment was proposed by the Center's Director, Dr. John Moeschler, and Valerie J. Bradley of the Human Services Research Institute in Cambridge, Massachusetts and Allen Crocker of Boston Children's Hospital agreed to carry out this short-term evaluation. The mutually agreed-upon goals of the project were to:

- Assess the Center's assets and challenges;
- Analyze the context within which the Center functions and the external forces likely to influence the Center's future;
- Assess the Center's internal organizational dynamics;
- Propose recommendations regarding any needed administrative, programmatic, and organizational changes.

Method

In order to achieve these objectives, several activities were undertaken. The first step was to meet with Center staff as a group and to determine their expectations for the project. It was also an opportunity to elicit staff responses regarding the organization's activities, strengths, and weaknesses, and to generate suggestions for organizational improvements and future objectives. Following the full staff meeting, interviews were conducted with all staff members -- in almost all cases, on an individual basis. Interviews were also conducted with key individuals at the Hitchcock Clinic, the Department of Maternal and Child Health, and the New Hampshire Bureau of Special Medical Services. In addition to these interviews, a second site visit was conducted by Dr. Crocker.

Finally, several documents were reviewed by the consultants including the UAP proposal, the Hood Center proposal, budget trend information, staff qualifications and other background material on the Center.

Expectations

During the full staff meeting held at the beginning of this assessment, several expectations for this evaluation and review were expressed. They are included here as a means of introducing the evaluation findings:

- Will provide a means to observe the Center from multiple prospects;
- Should help to understand what has been going on;
- Will help to determine how the Center fits in the Medical Center;
- Should assist in breaking down walls within the Center that lead to isolation
- Will assist in determining the role of support staff and the Office Manager;
- Should facilitate the development of priorities
- Should contribute to an understanding of the history of the Center;
- Will help to develop an overall philosophy for the Center and to determine what the common purposes are;
- Should create a more inclusive planning process;
- Will assist in determining appropriate roles for staff;
- Will help to chart a course for the future;
- Should help staff to understand relationship between research and clinical activities;
- Will help to understand the impact of the move to the new building;
- Should contribute to an understanding of the relationship of the Center to the UAP;
- Will hopefully provide a mechanism for continued dialogue and communication.

Structure of the Report

The analysis begins with a description of the Center and the ways in which it is viewed by external actors. The next two sections describe the assets of the organization as well as the challenges. These sections are followed by an

analysis of the external and internal organizational context. The final section includes recommendations about the future structure and direction of the Center.

II. Organizational Description and Image

Activities

The Clinical Genetics and Child Development Center provides both clinical and research functions. The clinical activities include the child development clinic, the genetics/dysmorphology clinic, the prenatal diagnosis program, the intensive care nursery developmental follow-up clinic, the genetic services program, the Down Syndrome clinic, and the school performance clinic.

With respect to research, the Center is the recipient of the following research grants:

- "Ethical Issues Arising Out of the Human Genome Project" (NIH);
- "Project TRAIL: Linkage between Neonatal Intensive Care and Special Education: (NH Bureau of Special Education);
- "Information and Technical Assistance for Educators, Related Service Providers and Parents of Preschool Children with Genetic and Prenatally Determined Disabilities" (NH Bureau of Special Education);
- "Early Use of Total Communication with Down Syndrome Children: (OSEP);
- "Collaborative Medical and Developmental Support Services for Children with Genetic and Prenatally Determined Disorders" (OSEP).

In addition to these specific projects, the Hood Center, which is now a part of the larger Center, also has a research mandate aimed at the needs of families who have children with disabilities.

Funding Support

Funding for the Center, is channeled through the Mary Hitchcock Clinic and the Department of Maternal and Child Health (MCH) in the Dartmouth Medical School (DMS). The Hitchcock Clinic has increasingly taken over the billing and administrative responsibilities associated with the Center's clinical activities, and DMS monitors and administers the Center's grant funds. The Center does not receive any revenue directly. The bulk of the Center's operating budget comes from so-called "soft" money sources and from fees. The only ongoing, or "hard" money, comes from DMS in the form of a tenured position and part-time secretarial support. To serve as a funding conduit for the Center, the Medical School assesses an overhead rate of 20%.

Organizational Structure

The lines of authority between the Center and the Medical Center (Clinic, Hospital, and Medical School) are complex. Some of the Center staff receive paychecks from the Clinic including the Associate Director for Child Development, genetic counselors and some secretarial support. The majority of the staff receive paychecks from the College and are employees of the Medical School. These multiple supervisory and payment relationships add to the confusion surrounding the Center's functioning and make lines of authority and accountability within the Center difficult to ascertain.

There are several major program areas within the Center including Child Developmental Programs, Research, Clinical Genetics Programs, Infancy and Early Childhood Activities (UAP), and the Hood Research Center. The Director of the Center is also the director of the Clinical Genetics Programs and the two Associate Directors are responsible for Child Development and

Research respectively. The new Director of the Hood Research Center will also direct Infancy and Early Childhood activities for the UAP.

Support services for the Center are provided by the Hitchcock Clinic, by MCH and the Center's Office Manager who in turn supervises the secretarial and clerical staff. In addition to the Center's core staff, there are also several consultants that work directly with the clinical programs.

Perceptions of the Center

As part of this inquiry, key informants were asked to characterize their impressions of the Center. The following are some of the responses:

- "No longer the only game in town;"
- "Willing to do statewide outreach;"
- "Good presence"
- "Has a lot of credibility"
- "Not as visible as they should be;"
- "Physically isolated;"
- "Don't know where they're headed;"
- "Good with patients;"
- "Disorganized;"
- "Need more definition;"
- "Not a money-making operation;"
- "Clinic piece is mysterious;"
- "Frustrating trying to figure out what's going on;"

These comments and other information obtained through interviews strongly suggest the need for Center staff to make a concerted effort to develop

a coherent image and mission and also to actively reach out to the surrounding medical community to facilitate an enhanced understanding of the functions and goals of the Center. This process will be greatly facilitated by implementation of the internal administrative changes and planning procedures subsequently recommended in this report.

III. Strengths and Assets of the Organization

Several strengths and assets of the Center were identified in the initial full staff meeting:

- The Center is connected to communities in the state;
- It is the only tertiary care facility in New Hampshire;
- There is a positive interaction between staff and families;
- The Center is a manageable size with less rigid boundaries which in turn facilitates communication;
- The staff are dedicated;
- The Center is flexible;
- There is a holistic approach to the problems of children and families;
- The Center is able to provide longitudinal attention to clients;
- The Center has independence within the institution;
- The Department Chair and the administrative staff are supportive of the Center's activities;
- There is an informality which allows staff to be "personal" with families;
- There is humor;
- There is no "assembly line" feeling;
- People go beyond their "job description" and do what it takes;
- People are available to each other;
- There are connections with peers in other states;

Several other strengths and assets became apparent during the interviews. First, the Center has developed an extraordinary track record in garnering support within the state from the New Hampshire Department of Special Education and the Bureau of Special Medical Services as well as the larger medical community at Dartmouth. Further, the Center has used its energies in the ambitious pursuit of numerous federal grants that have enriched the Center and made the marriage of clinical activities and research a reality if not a perfect union. Finally, the Center has been successful at attracting private foundation funds to support an ongoing research agenda. This diversified funding base is a major asset for the Center and one that would be the envy of similar enterprises around the country.

The recent affiliation with the New Hampshire UAP also provides a strong foundation for the attraction of additional financial support for training activities and research. Further, the affiliation provides the Center with an entree to statewide planning and policy making forums that will in turn enhance the Center's standing and prestige.

Finally, the staff at the Center are also an enormously valuable asset. They have a rich background in the both the delivery of clinical services as well as the conduct of high quality research. Many have been in their respective fields for several years and have developed a level of sophistication and competence that would be difficult to duplicate. In addition to the level of competence, a number of the staff have been with the Center for a substantial portion of their careers -- in one instance for 14 years. This longevity provides a continuity and coherence to the clinical aspects of the Center in particular.

IV. Challenges Facing the Center

Center staff also identified some challenges that they feel confront the Center and that need to be addressed. Their comments have been grouped under larger areas of concern.

Communication and Planning

- Lack of formal and informal communication to staff regarding various center activities;
- Varying schedules that make communication difficult;
- Lack of time to plan together and to evaluate how the Center is doing;
- No administrative support to facilitate planning and communication;
- Problems in maintaining communication with external consultants;
- Inadequate communication between professionals and support staff, and insufficient respect/regard for the concerns of administrative staff;
- Little communication with the Institute on Disability;

Worklife/Working Conditions

- Time constraints, and more work than can be done;
- Changing work demands that lead to inefficiency;
- Conflicting priorities including teaching versus direct services, means some activities have to be done on your own time;
- Continuing concern regarding funding; in turn results in uncertainty regarding what resources to count on and two classes of staff -- temporary (grant funded) and other;
- Lack of expertise in data management and computers, antiquated equipment, and lack of "trouble-shooting" resources when there are computer problems;
- Lack of understanding of workload of staff.
- Isolation from colleagues;
- Lack of space;

Evaluation and Feedback

- Need for information about workload norms and best practice regarding clinical activities;
- Not enough feedback on performance both internally as well as from clients including longitudinal information on the progress of particular children;
- Don't give ourselves enough credit for what the Center does;
- Lack of a structure for employee evaluations and development of employee goals and objectives;

External Relationships

- Complexity of the Center's structure and its relationship to the 3 institutions in the medical center complicate the administrative issues and also lead to inefficiency;
- Inadequate understanding of who the center is and lack of time to do dissemination to Department and the hospital leads to inappropriate referrals (e.g., need for more of a relationship between genetics and prenatal medicine);
- Lack of recognition from other parts of the institution and are not used by others as a resource on child development;
- Not part of a large multipurpose University with multiple graduate schools;

Administration

- Lack of any internal budget for the Center;
- The leadership of the Center is not trained in administration and are asked to wear numerous hats;

Communication and Planning. The interviews provided additional information on communication-related issues. The primary problem is that there is no formal mechanism to communicate information to the staff. As a result, very few people really understand the mission of the UAP nor the role that George Singer will play with respect to the Hood Center and the rest of the organization. Though staff meetings have been attempted from time to time, most of those interviewed noted that they did not fill this communication void, that some staff came late, that there was no agenda developed ahead of

time, and that the issues discussed were not generally relevant. In any event, regardless of the success of these staff meetings, none has been held in several months.

Further, the multiple time commitments among staff, and among the Center's leadership in particular, have exacerbated the communication problems intensifying the need for formal mechanisms. These problems are acutely felt among the support staff who must answer queries on the phone and who are many times not informed about the schedules or whereabouts of particular staff. This lack of communication can have ramifications for the image of the Center to the external community.

Because many staff have not been direct participants in the such activities as the UAP and Hood Center, there is a feeling that they are not part of the overall planning of the Center and that their views and opinions are not valued. Again, because there are no inclusive formal planning activities, the perception has grown that many are locked out of relevant discussions about the Center's mission and future.

Worklife/Workload. Interestingly, the challenges noted above under this category were not echoed significantly during the interviews. It may be that concerns about time and priorities are at heart part of the communication and inclusion issues. To the extent that people do not feel in control of their workload and situation through inclusion and participation, they may tend to feel that their jobs are unpredictable and onerous. In fact, most of those interviewed enjoy what they do and feel that the Center offers them a valued means of making a contribution to the lives of people with disabilities and their

families. The concerns about workload, therefore, appear to be related to communication issues as well as recognition and feedback issues discussed below.

Evaluation and Feedback. The interviews reinforced the concerns about feedback described at the staff retreat. There is a general feeling that, with the exception of those working in grant-supported positions, that there is no formal recognition and review of performance. Because the Center staff are earnestly interested in what they do, they are eager for feedback regarding how they are doing their jobs. At present, there is no formal process for providing this oversight. This limitation in aggravated by lines of supervision that are outside the Center. Specifically, many of the staff are formally members of the Department of Maternal and Child Health and, as such, receive their performance reviews from that part of the medical center. For others, they are titular members of the Clinic staff and for still others, there is no formal supervisory relationship.

With respect to other forms of evaluation, there is no formal process whereby the families who use clinic services, for instance, can express their satisfaction or lack of satisfaction with services rendered. There is also, outside of one of the research projects, no systematic follow-up of clients to determine longer terms effects of clinic interventions.

External Relationships. The interviews support the lack of a clear understanding on the part of the rest of the medical community regarding the mission and purposes of the Center. Such confusion can be seen in the comments regarding image noted in Part I. above.

Administrative Issues. The interviews strongly bear out the need for more administrative direction at the Center. Given the size and complexity of the organization, it is very difficult to manage the program given the fact that the Center's leadership really controls very little of its budget and therefore its own internal affairs. Staff report that it has been difficult to get operational budgets that help to assess the overall pace and distribution of revenues -- especially given the bifurcated nature of the revenue collection (i.e., Clinic and DMS). Without a coherent budget, planning and personnel decisions are extremely difficult if not impossible.

Further, even if the Center could become more self-contained and proactive, there is an insufficient administrative infrastructure and staffing level to carry out the needed administrative responsibilities including personnel, public relations, data collection and management, and other operational functions. As one interviewee noted, this work -- when it gets done -- is being done by "pieces of people."

A major reason why this fragmentation occurs is that those vested with the overall administration of the Center also are responsible for a significant amount of the Center's direct patient workload. Specifically, the Director, who is currently the only geneticist in New Hampshire, sees 60% of all Center patients himself (though his salary is only offset 20% by the Clinic). In fact, the Center's clinical capacity actually went down a full physician FTE when the previous director left taking with him an additional genetic counselor the fellow. Thus, even if procedures and plans were put into place, the Center leadership would have little time to carry them out given their current clinical as well as other responsibilities.

V. External Organizational Context

There are several major actors in the external environment of the Center including the New Hampshire Bureau of Special Medical Services (BSMS), the Dartmouth Medical School, the Hitchcock Clinic, and the Institute on Disability.

BSMS

Traditionally, the Center has received significant funding from BSMS. However, as a proportion of total funding, the Title V program is a less prominent source of revenue than it was five years ago. There are other factors that may also influence this revenue in the future. First, BSMS is now required to put the medical services that it funds out for competitive bid. This means that the sole-source relationship that the Center has had with BSMS will shortly end, at least in part. The first program to be affected will be the child development clinic which must prepare a bid sometime this Spring. Though the clinical genetics program will still be operated on a sole source basis, it is not clear that this relationship with BSMS will continue indefinitely.

Secondly, and related, there are increasing signs in the state that competition in the area of child development and genetics is developing -- at least in the southern part of the state. It is safe to say that the days when the Center could be assured of BSMS funding because of the uniqueness of their expertise may be coming to an end.

Finally, BSMS may be forced, in the future, to re-evaluate its clinic-based programs in light of the limitations of the model and the limited availability of Title V funding. Such re-evaluations have already occurred in states like

Massachusetts. Such shifts in program focus toward a consultative, third party driven system have significant ramifications for the future of the Center.

Dartmouth Medical School

A major actor in the environment of the Center is the Department of Maternal and Child Health within the Dartmouth Medical School. The Department provides significant administrative support and currently manages the lion's share of the budget. Based on historical arrangements, even fees collected by the Clinic for Center services are reverted to the Medical School through rebates.

The configuration of the Department -- combining pediatrics and obstetrics -- provides a unique setting for the Center which also combines a pre-natal and post natal emphasis.

Interviews at the Medical School suggest strong support for the Center and a willingness to work with Center staff to improve administrative, planning and budgeting procedures and work toward a more coherent and autonomous structure.

Hitchcock Clinic

The Hitchcock Clinic, which is made up of multiple sections/professional practices, has played an increasingly important role in the administration of the Center. They are now the primary administrative liaison with BSMS and meet periodically with staff in Concord. They have also taken over much of the billing for the Center's clinical activities and have supplied some management consultation -- particularly with respect to support staff at the Center.

The Clinic is a potential source of support for a senior management staff person at the Center. However, according to those interviewed, the relationship of the Center to the mission of the Clinic is not clear and those who make decisions about the allocation of resources will need to be persuaded about the significance of the Center's clinical activities and their contribution to the institution as a whole.

Like those interviewed at the Medical School, staff at the Clinic are very supportive of the Center's activities and appear committed to working with Center leadership to develop a more responsive, in-house administrative structure.

Institute on Disabilities

The Institute on Disabilities is the other portion of the New Hampshire University Affiliated Program. Though this relationship has many potential benefits for the Center, very little has been done to make connections between the two staffs. The premise of the UAP program nationally is to encourage cross-fertilization among disciplines and to provide a means of translating research into best practice and to provide researchers with a direct link to patient care. This promise is still only partially realized and additional and formal relationships need to be developed.

Other

Another important entity that functions in the environment of the Center is the Mary Hitchcock Memorial Hospital. Currently, neither the Center nor its staff have any formal relationship or recognition from that portion of the tripartite medical center. The Intensive Care Nursery at the Hospital depends

on Center staff to provide developmental support services (these services are billed by the Hospital but no funds are returned to the Clinic). Additionally, the Cyto-Genetics Lab and the Molecular Genetics Lab depend largely on the clinical genetics services programs for samples. This relationship and the interconnectedness of the Center's activities and those of Hospital have not been formally acknowledged. Certainly, as the new Children's Hospital within the larger Hospital begins to take shape, the importance of the Center's activities to the mission of such a program should be made explicit.

VI. Internal Organizational Context

There are several issues within the Center that affect the organizational culture including: 1) confusion over mission and tension between the clinical and research aspirations; 2) the lack of an explicit administrative structure ; 3) a perceived hierarchy rather than a participatory organizational culture; and 4) lack of clear leadership and organization building.

Confusion over Mission

Interviews with Center staff suggest a significant concern regarding the relationships between the research aspects of the Center and the clinical program. Many of those who provide clinical services have been there for several years and see the emergence of the research program as in some way threatening to the "caring" and client centered tradition of the clinical program. They are also unclear how the research will in turn be used to improve practice within the Center since no real formal mechanisms -- except on a project by project basis -- have been developed.

The concern with the integration of the research and practice aspects of the Center in part grow out of frustration over a lack of inclusion in the overall planning for the Center and participation in shaping the ongoing mission. If the two halves of this organization are going to work in a mutually beneficial fashion, more will have to be done to encourage communication and joint planning.

Without such communication, the Center is increasingly divided into two very distinct sub-organizations that function in an almost autonomous fashion. Staff loyalties as a result are not necessarily to the Center as a whole but to the individuals who manage their part of the organization.

The emergence of the research emphasis has also come about without the involvement of those who have been at the not been integrated into the Center's ongoing

Lack of an Explicit Administrative Structure

The Center currently has very few formal administrative procedures. This clearly contributes to the problems of communication as well as the expressed concern for feedback. There are no regularly scheduled staff meetings where staff can feel free to raise issues and where leadership can communicate policy. There are no personnel policies and supervision and reviews occur on an ad hoc basis. There is no formal orientation for new staff that help to familiarize them with the Center and its mission. Finally, there is no structured planning process that allows staff, in conjunction with leadership to reassess the Center's mission and future direction.

Hierarchy versus Inclusion and Participation

If staff were to draw a picture of the organization of the Center, it would undoubtedly show two or three people at the top and everyone else below. Throughout the interviews, individuals noted that leadership was somewhat "distant" and that staff was rarely consulted regarding their opinions. This perception is exacerbated by the fact that the leadership is made up of MDs and PhDs. The presence of two MDs at the top plays into stereotypes about doctors and their dictatorial style and the fact that the leadership is male and the rest of the staff is female also contributes to a sense of alienation from decision-making.

In many ways these perceptions of an organizational culture are largely shaped by the fact that the leadership is so involved in day-to-day clinical activities and have not had the time to shift their attention and working styles to conform with the other demands of the Center's programs.

Lack of Organization Building

Perhaps because of the personal styles of the Center's management, the demands on their time and the multiple roles that they play, very little time has been spent "nurturing" the organization. By nurturing, we mean spending time with staff, building consensus, hearing grievances, socializing, and generally taking the pulse of the organization. Because this function is not performed consistently, the sense of alienation mentioned above is exacerbated.

VII. Recommendations

Based on on-site interviews and document review as well as the suggestions made by staff, we offer the following recommendations:

- The Center should think about a new name that is less cumbersome, "snappier" and more in keeping with the multifarious nature of the Center's programs;

- The Center's administrative structure should be simplified by dividing the organization into a clinical division and a research division with Assistant Directors over each;

- The Center's clinical programs should be made a part of the Hitchcock Clinic (rather than continuing the hybrid arrangement that currently exists with the Medical School), and the Clinic should contribute to the support of a senior manager/administrator at the Center;

- Support for the new senior management position should be shared with the Medical School;

- The responsibilities of the senior manager should include personnel, development of administrative policies, public relations and marketing, as well as organization maintenance and nurturing;

- In line with the development of a new organizational structure, Center staff should participate in the development of a clearer mission statement that in turn can be used to educate key actors in the larger Dartmouth medical community and elsewhere;

- Leadership at the Mary Hitchcock Memorial Hospital should formally acknowledge the key role that the Center and its genetics expertise of necessity play in solidifying the Hospital's ability to market its speciality services within its new children's hospital;

- In addition to yearly all-staff meetings with the Institute on Disability, the UAP leadership should develop formal mechanisms for communication and cross site sharing;

- The role of the Hood Center within the Center and the UAP should be clearly defined and communicated to staff and others;

- A marketing plan should be developed in order to inform the Dartmouth community and others in the state regarding the nature of the Center's activities;

- Center leadership should meet with officials in BSMS to explore the Center's potential role in the future organization of Title V services including expansion of third party payments, elimination of the traditional "clinic" model and the development of a consultative role;

- Center leadership should meet with members of the Department of Maternal and Child Health in the Medical School in order to explore the possibility of developing a collaborative project on prevention of developmental disabilities (Dr. Crocker has offered to come to the Medical School to conduct seminars along these lines);

- Center leadership need to focus on the ramifications of the move and the very real possibility that not all staff can be accommodated within

the designated space. Given the current problems of organizational coherence and connectedness, the potential of splitting staff between two locations presents even more serious challenges.

- A conscious effort must be made to develop a mechanism for linking the research and clinical aspects of the programs through explicit communication and sharing among staffs and collaboration in grant planning and development;
- Clinic and DMS administrative staff should endeavor to provide the Center with a coherent budget that assists them in identifying revenues, indirect charges, third party payments, and so forth.
- Clinic administrators should add an additional FTE geneticist to the Center to relieve existing staff, to meet increased demand, and to allow the director more time to devote to other aspects of the Center.

The staff retreat also yielded a group of concrete recommendations for immediate action:

1. Develop an internal management plan and identify the resources necessary to carry it out;
2. Meet monthly as a group, develop an agenda beforehand and encourage punctuality; consider having weekly meetings among sub-groups within the Center (e.g., clinical staff, etc.);
3. Develop a functional data collection system;
4. Develop a personnel review process;
5. Establish a mechanism for quality assurance (e.g., consumer satisfaction);
6. Conduct an annual meeting with all staff that comprise the UAP in order to carry out joint planning and to share information about specific activities being carried out at each site;
7. Ensure that George Singer gets feedback from staff and vice versa;
8. Set up an ongoing planning and priority-setting process;
9. Determine appropriate location for Center;
10. Hold another staff retreat in 6 months to assess progress in implementing recommendations;
11. Make the move a positive experience;