IT’S THE LAW!! MFOFC Celebrates Passage of the Individual and Family Support Bill!

Massachusetts Families Organizing for Change (MFOFC) is celebrating the fruits of more than a decade of steadfast and determined advocacy with the recent passage of the bill entitled An Act to Support Citizens with Disabilities and Their Families. This family support legislation, originally filed in 1991 and the first of its kind in the Commonwealth, was signed into Chapter 71 of Massachusetts law by Acting Governor Jane Swift on July 26th. It requires most state agencies serving families of individuals with disabilities and chronic illness to develop annual plans for the use of their family support dollars. The state agencies must develop their plans through substantial consultation with individuals with disabilities and their families. The bill mandates collaboration between these agencies and sets forth a number of goals and principles to guide the implementation of family support. The state agencies included in this legislation are the Department of Mental Retardation, the Department of Mental Health, the Department of Public Health, the Massachusetts Rehabilitation Commission, the Massachusetts Commission for the Blind, the Massachusetts Commission for the Deaf and Hard of Hearing and the Division of Medical Assistance.

MFOFC wishes to express our thanks to the lead sponsors of the bill, Senator Mark Montigny (D-New Bedford) and Representative William Straus (D-Mattapoisett), for their efforts on behalf of individuals with disabilities and their families. Senator Montigny and Representative Straus understood the importance of this bill and fought for its passage. They believed that it would benefit all citizens in Massachusetts—and it will! The membership of MFOFC is grateful for their work and for the support of all of the bill’s co-sponsors: Senators Fred Berry (D-Peabody), Michael Knapik (D-Westfield), Stephen Lynch (D-South Boston), Andrea Nuciforo (D-Pittsfield) & Richard Tisei (R-Wakefield), and Representatives Daniel Bosley (D-North Adams), Kevin Fitzgerald (D-Boston), Benjamin Swan (D-Springfield), Timothy Toomey (D-Cambridge) & Michael Walsh (D-Boston).

At risk of sounding like we’ve just won an Academy Award, there are many other people we wish to thank for all of their encouragement and support, but they are just too numerous to mention! However, we would be quite remiss not to name just a few: House Ways & Means Chair John Rogers (D-Norwood) and House Speaker Thomas Finneran (D-Boston), the Massachusetts Developmental Disabilities Council, Human Services Research Institute and Mary Lou Maloney from Arc Massachusetts. Department of Mental Retardation Commissioner Gerry Morrissey is deserving of much appreciation for the great amount of time and energy he expended on behalf of the legislation.

Finally, we’re grateful for all of the individuals and families across the Commonwealth who somehow found time in their busy lives to make a contribution towards passage of the bill—writing, phoning or meeting with a legislator, going to the State House for a legislative hearing, providing oral or written testimony on behalf of the bill, participating in a telephone or e-mail tree, planning events, contacting the media and helping with fund raising. We can all be proud of our part in this successful campaign, secure in the knowledge that we have made and will continue to make a valuable contribution in the quality of life for individuals with disabilities and chronic illness. We know much work remains to be done as the legislation is implemented in all of the state agencies named in the bill, but we know a strong seed has been firmly planted and we’ll do whatever it takes to see it flourish and grow!
Central

Central Massachusetts Families Organizing for Change has been quite busy. We’ve implemented another successful Family Leadership Series which ended with our annual Family Works In Progress event. Our series this year included self-advocates as well as parents with cognitive disabilities. Thirteen families developed projects as a result of the series.

We are currently in the process of developing a unique collaboration with Worcester Communities of Care, and will be implementing a leadership series for youth who have brothers and sisters with developmental and/or emotional disabilities. We have seen an increase in the number of families interested in becoming part of the organization. To accommodate this, we will be hiring three Area Coordinators, one for the Worcester area, one for the North Central area, and one for the South Valley east and west areas. The increased interest has also spread to our Steering Committee—we’re looking at potentially voting in six new members.

CMFOC has managed to raise over $5,000 through various fundraising activities. We also have just completed another year of awarding $10,000 in grant monies to assist families and self-advocates in central Massachusetts with personal and community wide projects.

Much work has been done with organizing families to contact their representatives and senators about the Individual and Family Support Bill.

Southeast

The Southeast chapter of MFOFC is currently planning its 12th Family Leadership Series. The dates for this year’s Series are November 1st & 2nd, January 24th & 25th and March 21st & 22nd. The applications will go out in August. We are hoping again to have a group of participants who are culturally diverse and represent all areas of the region, all ages and different disabilities.

The Southeast region now has a full contingent of area coordinators! The area coordinators stay in touch with and share information with current and former participants of the Family Leadership Series, and help plan events for families in the Southeast. Each coordinator is a veteran of the Family

Western

Plans are well underway for our next Family Leadership Series, which will be held out in the beautiful Berkshire mountains in the town of Lenox. Our first two sessions will be in late winter and early spring, so we’re hoping for a relatively snowless winter like we had last year—or would it perhaps be wiser for us to hope we get new skis for Christmas??

As part of the 3-year grant from the federal Administrating Agency on Developmental Disabilities for which we’ve been a partner, families in the Athol area participated in a “mini-Family Leadership Series” this past May and were very positive about what they learned. A workshop on guardianship and estate planning has also been offered as part of the grant, and families have expressed interest for future trainings about social & recreational opportunities, sexuality & relationship training for parents and their children, parent training (especially for single mothers) and training for generic provider agencies. Another idea being explored is to develop a peer mentoring program that utilizes curriculum that is used in the peer mentor model in many after school programs.

Our Governing Board is currently in the process of developing a survey for our region’s membership to get their input and feedback regarding what projects, issues or ideas they may have for area and regional goals or objectives our group could take on in the next year or two. The Board has agreed to call each and every one of our members to ensure that everyone has an opportunity to be heard, as well as to indicate what level of involvement they would like to have in these efforts. As we all have discovered, there certainly never seems to be a lack of work to do!

Submitted by C.J. McGregor

Submitted by Dana Dansereau
Northeast

It has been a busy few months. Our ninth family leadership series was eventful with great speakers. Alan Ripp, who originally worked at the Institute for Community Inclusion and is now making good inclusion happen for children in the Newton public schools, spoke to the group about community. Gail Havelik from the Department of Public Health gave us all the ins and outs of public benefits. Since this was our legislative weekend, Mary Lou Maloney from Family to Family at Arc Massachusetts did her usual fabulous job of teaching Civics 101. Senator Tisei spoke eloquently about our need to advocate with the legislature. He has a sister with disabilities and understands and supports (and is a co-sponsor of) our Individual and Family Support Bill. Richard Howard, Esq. from Kotin, Crabtree and Strong spoke about the ADA and IDEA to help us better understand those laws.

We sponsored a Family Council Summit that brought members from six Family Support Provider Agencies as well as participation from Boston, Southeast and the Western MA chapters of Uniting Families for Change. The topic was "Building Better Communities through Partnership" and how different council members stretch their dollars.

On June 2, we hosted the "Together we Bargain, Divided we Beg" Family Leadership Reunion Brunch. We had a great turnout and our motivational speaker, Lynn Williams-Tonkin, channeled the group's energy to push for passage of our bill. There was lots of fun and prizes and networking for the many participants.

On another note, Operation HouseCall got some much-deserved recognition in Exceptional Parent Magazine's May edition. This project which is a joint effort of GBARC and Boston University Medical School exposes third year medical students to the daily routine of family life with a child with special needs. This program was highlighted in the U.S. Surgeon General's Listening Conference held last fall. There are over sixty volunteer families. All of the participants in the photos in the magazine are past family leadership participants! We are proud of all of the families and their participation in this program which makes such a positive contribution to the physician of the future.

Submitted by Susan Nadworny

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Leadership Series. Our network in the Southeast continues to grow and the area coordinators provide a valuable link to families throughout the region. The area coordinators are: Brockton ➔ Sue Stoehr (508-559-8908), Cape Cod & the Islands ➔ Diane Clemence-Shreiner (508-428-7288), Fall River ➔ Denise Fortin (508-676-6794), New Bedford ➔ Jorge Pagan (508-998-0848), Plymouth ➔ Kati Deneen (781-293-4217), and Taunton/Attleboro ➔ Dianne Huggon (508-823-3529). Please feel free to call your local coordinator should you have any thoughts or ideas that you wish to discuss.

Submitted by Emily Murog Nisenbaum

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Boston-Metro

Tom Taranto and I are still our region's coordinators for MFOFC, with Wayne Hines and Cathe Carpenter supporting our efforts. We all remain committed to work towards developing a stronger presence within our region. We have some ideas and contacts that may assist us, but what we need most of all are families in our region who are interested and willing to invest a little time and energy to help our region become better organized. Please use the contact info on the first page of this newsletter to get in touch with me if you also share our urgency to get up to speed with the rest of the state!

There has been some restructuring and movement of staff within the Boston Region of DMR. Now that things seem to be in place, we intend to begin working with Suzanna Chan, our Director of Family Support, to set up a meeting with Regional Director Gail Gillespie to discuss plans and funding options for a long overdue Family Leadership Series in our region.

We will be contacting families to let them know about the passage of our Individual and Family Support Bill (although most of you will have already been informed after reading this newsletter!) and the upcoming MFOFC annual meeting and celebration. We will also be asking for help in our efforts to establish another Family Leadershi Series in the Boston-Metro Region.

One of the most important things we plan to do is reach out to the Boston families who have been involved with the self-determination project to discuss how we can work together. There is so much talent, experience and wisdom in our region and we can't wait to harness it so that we can accomplish some amazing things for individuals with disabilities and their families!

Submitted by Jean Palmateer
From Facilities Planning to Full Community Membership   edited from a presentation given by Arc
Massachusetts Past President Donald Stewart at the Arc’s April 8, 2002 Annual Meeting

Massachusetts has a unique opportunity for full community membership for people served by the Department of Mental Retardation (DMR). We currently have a dual system, one for facilities and one for community programs. We have a facilities system of six locations: Fernald, Glavin, Hogan, Monson, Templeton and Wrentham (Dever is now closed) with 1200 people and 3600 employees.

Budgets are currently tight for DMR, to the point where all of us are concerned about quality of services. Community programs have severe dollar limitations, and we’re only a few dollars per hour over minimum wage for direct care workers. Recruitment and retention levels reveal that salaries for other community system workers are also a major problem.

Costs are higher at the facilities compared with the community system for four reasons:

- Aging physical plant
- Low census per location
- Residents with complex treatment plans
- Salary differences between most workers at the facilities vs. most workers in the community.

Here is a comparison of costs: $183,000 per year average cost in facilities vs. $134,000 per year for the community. The source of these numbers is the Facility Planning Working Group of the DMR strategic plan, which included members from Arc Massachusetts, Massachusetts Families Organizing for Change (MFOFC), and Massachusetts Advocates Standing Strong (MASS).

Choices for the Facilities

What are our choices? We can leave them all open, we can close some of them, or we can close all of them. Arc Mass, MFOFC and MASS all weigh in vigorously on closing the facilities in the next 3.5 years (by the start of CY 2006). It can be done, and we propose a top-level plan on closing them and moving people to the community with compassion and caring. DMR has closed multiple facilities in the past twenty years, and the DMR managers know how to do it.

What are the advantages of full closure?

1. An open facility bed could be filled by an individual who is placed there against his or her will. Available facility beds are always a potential placement for someone in the community. Given the cost, the only reasonable assumption is that those beds will be filled. In spite of excellent DMR management and goodwill from all involved, there always remains the potential risk that someone will be misplaced in a facility against their will. Many self-advocates, including the two MASS representatives to the Facility Planning Working Group, feel very strongly that this risk, however small, is unacceptable. The most famous occurrence of misplacement is that of the two women in Georgia whose case led to the Olmstead ruling by the Supreme Court.

2. In the post-Olmstead era, facilities are seen as outdated service models and no longer appropriate placements, given their restrictive institutional settings. Since the 1970s, a large number of service models for community and home supports have evolved, offering a far wider range of choices. DMR, families and individuals working together developed pilot programs and collected data that has resulted in proven service models. Thus, in our opinion, institutional settings like the state facilities have become programmatically marginalized, except for the dollars they consume.

Further, the national data included in the Facility Planning Working Group report shows the strong national trend away from facility settings. Massachusetts is the last New England state with multiple facility campuses, and may soon be the only New England state with any facilities.

3. Equal or better services to the medically fragile, behaviorally challenging and forensically involved are proven to work in settings other than the present six facilities. For medically fragile and behaviorally challenging individuals, the strong medical and academic resources that are available in Massachusetts’ community settings make them the preferred choice. We are fortunate to live in a state rich in medical skills and services that are offered and consumed here by people from around the globe.

In this environment rich in medical and behavioral service competence, it is not appropriate public policy for DMR to perpetuate an in-house system geared only to individuals with mental retardation. Experience in many service industries shows that in-house services invariably fall behind vibrant services in the community that must daily prove their worth and effectiveness. In summary, we see no future role for facilities for medical or behavioral services.

For the forensically involved, a strong multi-disciplinary team located near an academic medical facility is a clear preference for high-intensity services. The multi-disciplinary team is not a luxury, but an essential element in identifying causes and establishing treatments for people that often have significant undiscovered medical issues. No existing facilities are appropriate for a high-intensity program, nor are any of them well-positioned near an academic medical facility.

4. The operating cost analysis shows that closing all facilities is the clear preference for operating cost reasons. Given DMR’s role as fiduciary for public funds, we see that operating costs are an important issue. Further, we believe that cost savings from facility closure should be directed towards strengthening the community service system for the approximately 80,000 people receiving those services. The summary of the operating cost analysis uses assumptions agreed to by the facilities planning working group. Full closure is the lowest-operating cost choice, saving $421 million over ten years compared with leaving all
Of Record

facilities open. The operating cost savings is huge and sufficient reason alone to recommend that all facilities be closed by the beginning of CY2006.

5. Closing the facilities will avoid nearly all capital expenditures otherwise needed if the facilities remain open. The last major investment in the facilities was in the early 1980s. For the facilities to remain open, the working group report says that capital expenditures in the range of $25 million to $93 million (in February 2006 dollars) are required. Our view is that these numbers are low, and that the capital investment needed could range upwards to $210 million (February 2006 dollars).

We assumed that eliminating the deferred maintenance plus normal capital expenditures requires pro-active spending equal to three times the rate that the deferred maintenance accrued, or $10.5 million per year. Given that nearly all facility buildings are at least 35 years old with no new construction since the 1970s, the changing requirements of building standards, the ADA, and the unforeseen (and inevitable) surprises in capital maintenance and construction, we believe that the spending rate of $10.5 million should continue for a minimum of 20 years. Our estimate, therefore, is $210 million ($10.5 million times 20 years).

From a facility planning working group perspective, we recommend a capital expenditure estimate that is realistic, allows for surprises and includes some new buildings in the estimate. Keep in mind that facility buildings will be a minimum of 45-years old in FY2011, and at the end of life for commercial buildings. With that perspective, even the $210 million estimate may be low.

The high cost and uncertainty on capital expenditures can be avoided by DMR if the facilities are closed by the beginning of CY2006. In addition, the operating cost savings would be $421 million over the next ten years.

Annual Savings in Operating Expenses

By closing all facilities, the operating cost savings in 2008 would be $65 million per year in 2008 dollars, assuming a 3 percent rate of inflation. This is money that can be invested in the community system for some dramatic improvements:

- A major down payment on deferred salary increases in the community system. The amount of deferred salary is about $75 million per year in today’s dollars, assuming a deficit of $5000 for 15,000 people in the community system;
- Improved access to the health care system;
- Improved family support to keep people at home;

That is where the families are, as well as the jobs, the recreation and the learning opportunities. That is where we all live our lives. It is a privilege for all to be there. Let's open the doors, meet the post-Olmstead world with a strong proactive plan to minimize institutionalization, and think about our fiduciary responsibility to provide appropriate services with a fully integrated community system.

Matters of the Heart

Many Voices, Many Choices

On June 11, an event celebrating families and family support was held at the State House in Boston. The main focus of the event was to unveil and distribute a newly published family support booklet entitled Many Voices, Many Choices, and to honor the eleven families that are featured in this wonderful booklet. The legislative delegation representing these inspiring families was invited to attend and join in honoring the families. The purpose of the celebration was to:

- Highlight the importance and benefits of family support,
- Communicate the significant difference family support makes in the lives of families,
- Celebrate the diversity of families and the unique ways in which family support is used,
- Showcase the accomplishments of families using family support, and
- Promote support for passage of the Individual and Family Support Bill.

The Celebration of Family Support was hosted by the Department of Mental Retardation in partnership with Arc Massachusetts, MFOFC, The Massachusetts Developmental Disabilities Council, the Federation for Children with Special Needs and the Institute for Community Inclusion. The event was sponsored in part by a grant from the Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services.

Many of the families featured in the booklet are former participants in the Family Leadership. Sandy Kinney from Marion was one of two family members invited to speak at this event and provided moving testimony to those in the audience about how vital responsive, flexible family support has been to her family. The second family member invited to speak was Eula Drummer, a grandparent from Springfield. Eula offered the audience a unique perspective of the issues faced by grandparents raising grandchildren with disabilities and their unique family support needs. We were very excited and proud to celebrate with these very wonderful families and with the more than 150 people who were at the event!

MFOFC has copies of the Many Voices, Many Choices booklet. If you'd like one, please call 800-406-3632.
A Letter of Protest...

Mr. Howie Carr  
c/o WRKO News Talk 680 AM  
20 Guest Street, 3rd Floor  
Brighton, MA 02135  

Mr. Carr,

I realize this letter may only serve to provide fodder for your charming wit and humor, but I wish to express my outrage about two items that recently aired on your radio program. The first is a promo that I’ve heard several times in the last week. A man’s voice intones, “Howie Carr, a man who’s not concerned with his image.” Then a woman says, “Yeah, Howie, you’re a lot smarter than you look... ‘course you look like a retard.” The second item is a discussion you had a few weeks ago about an incident on an airplane involving a person with mental retardation. Among your truly erudite comments was, “Why do they even let these people on planes? They should make them rent a car from Hertz and drive.” Your assistant chimed in with something like, “What was going on there, the Brazilian Retard Convention?”

As the father of three young adults with significant developmental disabilities, I resent the insensitivity and mean-spirited nature of those words. My children are all contributing members of our community and have every right to be treated with dignity and respect. My oldest son works in a supermarket and volunteers at three other businesses. My daughter brings kindness and comfort to others in her volunteer positions at the local hospital and at the Holyoke Soldiers Home. My youngest son has also started volunteering as he explores opportunities in the workplace. Each has people in their lives who care about them and value the contribution they bring to the world.

What right do you have to belittle people like my children? Through no fault of their own, they face daily challenges resulting from their disabilities, the greatest of which is trying to overcome the ignorance and attitudes typified by your words. Like you, I believe the actions and behaviors of people with cognitive disabilities should be subject to the same standard as every other citizen in our country. What they should NOT be subjected to is the vile and hateful intolerance represented by your callous remarks.

Would you please open your eyes instead of your mouth to realize the hurtful impact this type of programming has—directly upon individuals with disabilities and their families, as well as indirectly upon those who may consider it a tact approval of hateful speech directed at a vulnerable minority? I certainly hope none of your five daughters gives birth to a child with disabilities—what a shame it would be that their father will have made the world an even more difficult place for both his children and his grandchildren to live.

Sincerely,

Dana Dansereau  
38 Cedar Lane  
Westfield, MA 01085

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A Letter to the Family MATTERS Editor

As I've have attended various MFOFC reunions and gatherings during the past few years, I can't help but notice the absence of so many of our compatriots who were always there before. Upon asking several individuals who know these people as to how they are doing, the answer is either “I have no idea...” or “Their son or daughter now has a satisfactory day/residential placement.” While the word satisfactory is great to hear, their absence is disturbing to me.

Maybe I am a minority of one, but I sincerely feel that my belonging to and participating in MFOFC is not just about me or my family, but rather about trying to make the overall delivery care system better—regardless of personal gain. The education that I receive at meetings and through various organizational materials has caused me to greatly raise my personal standard as to what programs and services I consider acceptable for my son. If we all can stay actively involved and use the skills we gained in a Family Leadership Series to work for better support services and care, the possibility of success for everyone is greatly enhanced.

Organizations such as MFOFC, the ARCs, Massachusetts Advocates Standing Strong, Family to Family and the DMR Citizen Advisory Boards all desire and need citizen participation. If we don't all join in and do our part, then the possibility of participants who do not share our goals and values usurping these organizations is greatly enhanced.

I know we are all so busy and that probably will always be the case, but I doubt there is anyone who could not spare 4 hours once a month to participate in one of these groups. It's just a matter of where the onward quest for a better society fits into your personal agenda.

Ron Asbjornson  
Proud Parent of Paul
Financial MATTERS

The Power of Asking... submitted by Kathi Hackett, Southeast Mass. Families Organizing for Change

Lynn Williams-Tonkin has been a popular speaker at most of the Family Leadership Series held across the state. A theme Lynn has spoken about is “The Power of Asking”. Throughout our lives, we find ourselves—not always willingly—having to ask for something that we need for someone in our family or for a group or organization we belong to. Whether it be asking for support, for resources or for a donation, many of us struggle with what to do and how to do it. Lynn’s presentation is very thought provoking and outlines “The Top Ten Reasons to Dare to Ask”. They are:

10) It’s easier than you think
9) It sure is more fun than cleaning
8) Practice makes perfect
7) Someone else might beat you to it
6) You might get what you ask for
5) Being told “no thanks” is not that bad
4) It never hurts to try
3) It works more often than not
2) Most people don’t “do” because they are not asked!
1) They might say yes!

Lynn has helped many of us to re-frame our thinking and has supported us to have a more open mind and a more comfortable attitude toward “asking”. It may never be EASY, but with Lynn’s humor and wisdom, many of us have given it a go! So go ahead and TRY IT.....YOU MIGHT LIKE IT......and you may get some great results!

...so now we’ll ask YOU!

Are you looking for a great organization to support? Well, have we got one for you to consider—us! As you know, MFOFC operates on a shoestring budget—sometimes we have to use Velcro when the shoestring breaks! We’d greatly appreciate any contribution you may wish to consider. Your donation is tax deductible, so please let us know if you’d like a receipt.

Please make your check payable and mail to: Massachusetts Families Organizing for Change
P.O. Box 61
Raynham, MA 02768

Summer Solstice Celebration! by Susan Nadworny, Northeast Mass. Families Organizing for Change

Massachusetts Families Organizing for Change (MFOFC) and Parents for Residential Reform (PFRR) recently partnered together to host an unforgettable evening. The Summer Solstice Celebration event was held June 21, with a full moon overlooking Boston Harbor at Pier Four Restaurant. Over two hundred guests joined us for a magical evening of great food, great company and a great time. We danced the night away to the music of the Marsels (the New England Patriots Superbowl Party band!) and raised much needed funds for MFOFC’s overall mission of empowering families and specifically to help with the expense of this quarterly newsletter.

These two family centered organizations also raised over ten thousand dollars for adolescents with disabilities living in state care with little or no family involvement. We look forward to providing each child with an age appropriate gift during the holidays to show them they are remembered and cared about.

U.S. Senator John Kerry, Attorney Tim Sindelar from the Disability Law Center, and Richard Sheola, President of the Public Services Sector for Value Options, Inc. were honored with “Powerful Friends Awards” for their advocacy and hard work on behalf of people with disabilities.

We thank the many people who contributed to the success of this evening with their time, energy and efforts. It was truly an honor to be in the presence of so many outstanding advocates for our children!

Editor’s note: MFOFC is deeply indebted to Susan for her many, many hours of work on this event and for her charm and grace as MFOFC’s representative on the Planning Committee!
Very Important **MATTERS!!!**

A committee has formed to plan a celebration of the passage of our *Individual & Family Support Bill*! The celebration will be held sometime this fall, perhaps in conjunction with the MFOFC Annual Meeting. Please periodically check our website for further information. The address is: www.communitygateway.org/mfofc or call the office at 1-800-406-3632. LLLLLet’s get ready to partaaaay!!!

**Subscription to Family MATTERS** is free! If you did not receive this newsletter in the mail and would like to be placed on our mailing list, please use our address, phone number, fax number or e-mail address listed in this box and give us the following information:

- Name
- City/State/Zip
- Street Address or PO Box #
- Phone Number

Please feel free to refer us to another family member or friend!

**About Massachusetts Families Organizing for Change…**

We are a statewide, grassroots coalition of families with children and adults who have disabilities and/or chronic illness. We are actively organizing our talents and our experiences with the conviction that family and individual supports should be comprehensive and flexible.