

**Sedgwick County Task Force
on Developmental Disabilities and Mental Illness**

Final Report

**Presented to the
Board of Sedgwick County Commissioners
December 6, 2006**

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I. Background

Prompted by growing concerns from the community it serves, in March, 2006, the Sedgwick County Board of County Commissioners created and made appointments to the Sedgwick County Task Force on Developmental Disabilities and Mental Illness.

The Task Force was assigned the following mission:

- Investigate and document the extent to which persons in Sedgwick County who have developmental disabilities (DD) and mental illness (MI) or who demonstrate extreme and dangerous behaviors without a mental health diagnosis (i.e., sexually inappropriate behaviors, etc.) are receiving appropriate services to meet their unique support needs;
- Identify and document the consequences, including unintended risks to other persons in the community, especially other persons with DD, which result from inappropriate or under-funded services to persons who have a dual diagnosis or who demonstrate difficult-to-manage behaviors without a diagnosis;
- Recommend to the Sedgwick County Board of County Commissioners actions the County can initiate or influence in order to improve services to persons who have a dual diagnosis or who demonstrate difficult-to-manage behaviors without a diagnosis, and at the same time, also protect the interests of other persons with DD as well as those in the broader community.

The twelve Task Force members appointed by the Board represent a diversity of interests and experience, and include parents of persons with DD as well as professionals with expertise in developmental disabilities, mental health, social services and law enforcement.

II. Executive Summary

Members of the Ad Hoc Task Force identified the following problems that create the potential that people will be harmed by individuals who have developmental disabilities and who engage in extreme aggressive behaviors:

- While the number of individuals who engage in these behaviors is relatively small (estimated at fewer than 100), the number is growing and the system is not adapting to the dangers they present.
- The system was not designed to meet this type of disability support need and community programs are not equipped to safely support this population.
- There are very few community supports available to individuals who require immediate intervention to address extreme aggressive behaviors other than the services provided by developmental disability programs. Inpatient supports are commonly denied to people who create the risk of harm to others.
- People who engage in extreme aggressive behaviors are commonly served in the same programs as people with disabilities who can easily be victimized.
- Law enforcement and other community systems also lack specialized services or interventions that would be effective for this population.
- There is a need for better coordination to assist people in accessing community mental health supports.
- Community service providers are risking their future when they accept the liability of serving individuals who create a danger to themselves and others.

To address the problems that were identified, Task Force members offer the following recommendations for action by the Board of County Commissioners to best serve persons with dual diagnosis and extreme aggressive behaviors, and to minimize the dangers their behaviors create for others:

- Create alternative placements to more safely support those who cannot be safely supported in an existing community home.
- Create a response team made up of individuals from across systems who can respond and lend assistance during crisis situations.

- Contract for specialized support programs that are designed to provide the type of specialized supports these individuals require
- Implement policy that prevents serving those who present a danger alongside those who may be easily victimized
- Determine when it is appropriate for a community service provider to decline to serve someone who poses a danger;
- Implement various types of training for professionals from various service systems to ensure better coordination of community resources;
- Expand the role of the CDDO as a gatekeeper to assure a more accurate and complete transition to adult services for those with a history of extreme aggressive behaviors; and
- Create a position to coordinate services between the Mental Health and Developmental Disabilities Systems.

The Task Force also offers recommendations to the County Commission to influence action by the State of Kansas, which plays a key role in funding and providing oversight for community programs:

- Ensure timely access to sufficient reimbursement that corresponds with the additional cost of serving this population;
- Address the need for higher reimbursement rates that provide for the level of training and skill that direct-care professionals who work with this population require;
- Effectively manage capacity at state hospitals to ensure that the emergent needs of persons with extreme aggressive behaviors will be addressed when needed;
- Provide specific clarification concerning the requirements for determining that an individual cannot be served safely in the community;
- Expand early behavioral intervention for children prior to age five;
- Develop a procedure to implement needed interventions for individuals in this population, even when they may not consent;
- Require child placing agencies to fully disclose records for children who have a history of engaging in these behaviors; and
- Pursue amendments to the 1998 Program Instruction Manual that speaks to the coordination between developmental disabilities and mental health programs.

III. Approach to the Assignment

From the beginning of our assignment, we were keenly aware that the subject area of our mission represented an emerging problem not only in Sedgwick County, but throughout the state of Kansas. Until the formation of the Task Force, it appeared there had been no comprehensive effort by state and local policymakers to document or understand the extent and severity of the problem.

Over a series of 13 meetings, our approach to the Task Force mission included the following:

- Reviewing state and local laws, policies and regulations related to the delivery of DD and mental health (MH) services;
- Learning of the organizational structure and responsibilities for the delivery of DD and MH services in Sedgwick County and in Kansas;
- Receiving testimony from management and program staff from local developmental disability agencies that deliver services to children and adults with DD;
- Receiving testimony from persons who have a family member with a dual diagnosis (DD and MI), or very difficult to manage behaviors;
- Learning from mental health experts about the barriers in Sedgwick County to in-patient psychiatric services for persons with DD;
- Engaging in conversations with local law enforcement professionals about the limitations of law enforcement strategies in dealing with persons who have a dual diagnosis; and
- Discussing the nature and scope of the problem with leaders from the Kansas Department of Social and Rehabilitation Services who are responsible for the delivery of state DD and MH services.

Several assumptions guided our inquiry:

- Our community has an obligation to see that all residents with DD, regardless of the extent and severity of their challenges, have services that attempt to help them function more effectively in their lives;
- As members of our community, all persons with DD, including those with serious mental illness and/or violent behaviors, have rights and responsibilities to others in the community. Community services for this population cannot be provided at the expense of the safety of others in the

community, most notably other individuals with DD who are especially vulnerable to those with aggressive and violent behaviors; and

- Solutions to the challenges of serving persons with a dual diagnosis are a shared responsibility across many agencies, sectors and levels of government. Sedgwick County is to be commended for raising the profile of this problem, and clearly has a leadership role in addressing it as do other community partners representing developmental disabilities, mental health, education, social services and law enforcement. However, the central leadership role in addressing the problem rests with state government due to its legislative responsibility and access to the greatest resources for services to persons with DD. The problems identified in this report cannot be resolved without a strong, sustained partnership between the state and Sedgwick County governments.

IV. Overview of the Report

Our work over the past six months led us to the following broad conclusions, which are detailed throughout the remainder of this report:

- 1) In general, persons with DD who live in Sedgwick County receive excellent services. First, Sedgwick County provides local dollars to enhance the quality of services, beyond what state funding provides. Second, Sedgwick County's CDDO provides strong leadership in setting high service standards, and in giving persons served and their families choices in providers; and third, community service providers in Sedgwick County are committed to providing the best possible services for the persons they serve, even when that means supplementing public funding;
- 2) A small but significant exception to the overall high quality of services for persons with DD must be noted, however. In some instances persons in our community who have a dual diagnosis and/or extreme or aggressive behaviors, do not receive adequate community services and have very limited access to state hospital services. State officials are aware of the problem and are open to policy advice from local DD agencies, but as of yet, have no policy solutions;
- 3) Children and adults with DD who demonstrate extreme and aggressive behaviors are a small, but growing group among the total population of people with DD in Sedgwick County. The total number of individuals in this category is estimated to be less than 100 people out of more than 2,000 who are currently eligible for services;
- 4) The current community service delivery system for persons with DD was not designed to serve this population. Local DD service providers in Sedgwick County do not have the staffing, financial resources, specialized expertise or state regulatory framework to effectively serve many of them; requiring these agencies to do so is at the expense of safety and service

quality to the vast majority of other persons with DD who do not have mental illness, or extreme aggressive behaviors;

- 5) Placing people with extreme aggressive behaviors in current local developmental disability programs creates a serious and unacceptable threat to the safety of others; and
- 6) Working in concert, state government and local communities must immediately develop more specialized and structured services to effectively meet the needs of this population and protect the safety of others in the community. Such an effort cannot be undertaken without additional financial resources. Additionally, interdisciplinary partnerships among developmental disabilities, mental health, education, foster care and law enforcement agencies, along with support from advocacy groups will be needed to accomplish this goal.

V. Defining the Problem

1. **There is a growing number of Sedgwick County adults and children with developmental disabilities and mental illness and/or extreme aggressive behaviors that make them an unacceptable risk to themselves, others around them and surrounding property.**

- Data from the State's client data system (BASIS) indicates that nearly 40% of individuals who are eligible for MR/DD services in Sedgwick County also have some type of mental health diagnosis. We estimate that fewer than 100 people presently served locally engage in the extreme aggressive behaviors.
- Some individuals within this population engage in predatory sexual behavior. These individuals require constant and very costly supervision to ensure that no one is victimized.
- While many community service providers have traditionally asserted that nearly anyone who qualifies for MR/DD services can and should be served in the community, there is a growing number of individuals who cannot be served safely within current service models and at current funding levels.
- Several children from Sedgwick County who are served at an intensive inpatient residential facility in Paola, Lakemary Center, because they have greater support needs than can be provided by current community services. Failure to create a local service model for extraordinary behavioral supports means that the problem of serving these children has only been delayed until they are older and return to our community.
- We predict a growing number of individuals will require intensive services in the future. Rainbows United and other providers of

services to children indicate that there are more children with severe behavioral issues that will be seeking community supports from the MR/DD system when they are old enough to qualify.

- A combination of foster-care placement and DD and mental health supports is presently the alternative to supporting a child in her or his home. Unfortunately, few foster homes have the resources and experience required to meet the extreme behavioral needs of these children. Failing to meet their needs as a child means supporting them in adult DD services may be even more difficult.
- SRS scheduled community meetings across Kansas during the summer of 2006 to gather input from families of children with autism. A common theme in the feedback that was received was the lack of resources in communities to appropriately deal with extreme behaviors.
- Families expressed to the Task Force their feelings of fear and futility to meet the needs of family members with disabilities who engage in extreme aggressive behaviors. Among their concerns was the lack of other resources to manage these behaviors when family members are no longer available to do so.
- The Task Force heard reports about individuals who fall into this category who did cause harm to themselves, family members, support staff, or other members of the community. Examples of extreme aggressive behaviors reported by families and service providers include:
 - i. A woman's extreme behaviors included regularly biting out pieces of her own skin, running into traffic, and banging her head on the street;
 - ii. One man protested an issue by setting his bed on fire, which made the group home uninhabitable for him and two other people with disabilities;
 - iii. A man with a history of arson and aggression toward others was admitted for inpatient psychiatric care but was discharged after four days with orders not to admit him again because his behaviors created a risk of harm to others, leaving the provider with no other options to manage his behaviors or protect others;
 - iv. A person served became upset and hit a staff member on the head with a mallet used in the workplace, causing serious injury to the employee. The employing agency did allow the staff member to file charges against the individual

in the incident, but received criticism from SRS for this decision;¹ and

- v. A man with severe disabilities broke free of agency staff and did significant damage to a community business office. During the incident, he threw an iron water meter cover at a staff member in the office, narrowly missing her head.

- The scope and rigor of expectations placed upon community DD service providers is unprecedented. Unlike the DD system, other systems that must serve anyone who qualifies have the capability to impose interventions that have not been approved by the individual to the extent necessary to prevent harm from occurring. Examples of these interventions include hospitalization or use of restraint or seclusion.
- When assistance from a mental retardation state hospital is accessed for these individuals, the expectation is that the community service provider will be able to create a support model in a relatively short period of time that will allow the individual to be served in the community. This expectation does not take into consideration the limitations of community service providers to duplicate the level of staffing, training, facilities and associated resources that would allow them to implement recommendations from hospital staff. Nor does it take into consideration the very limited ability of community providers to utilize seclusion, physical restraint, or other behavioral interventions to prevent harm or property damage.

2. The Kansas Developmental Disabilities Reform Act created an expectation for community-based services more than 10 years ago, but did not adequately address the issue of serving people with extreme aggressive behaviors. Because of this, community programs are not designed or empowered to safely support this population.

- The expectation of community service providers is to utilize the “least restrictive” setting or intervention before any option that may be more restrictive is utilized. While state regulations, including KAR 30-63-23, speak to the possibility of utilizing more restrictive interventions (seclusion, restraint, hospitalization, etc.) when appropriate, this possibility has not been embraced by the state or most stakeholders.

¹ SRS interpretation of regulations discourages involvement of law enforcement in cases where persons served break the law. This interpretation is not consistent across service systems. This removes natural consequences incurred by individuals who are not served in this system. The individual accused in this case was not prosecuted by local authorities.

- Intensive levels of supervision required to keep communities safe actually create support models that are more restrictive than hospital settings. In essence, an individual may have more personal freedom on a state hospital campus than they have in a community placement due to the level of staff oversight that is required in the community to prevent harm.
- Obtaining consent of the eligible individual or guardian in order to implement restrictive interventions is a problem at all levels. The state hospitals indicate an inability to serve individuals if there is no appropriate authorization from the individual or guardian to do so. Individuals who can legally select their own services can choose to remain in the community despite the risk of harm to themselves or others.
- Access to community DD services may be withheld from individuals who have been determined unsafe for community services by the SRS Secretary. Agencies that have made such a case to the Secretary indicate they were not supported by the state.
- Individuals who do pose a threat to themselves or others require intensive support settings geared specifically to the individual. While such settings do not remove the possibility of harm to the individual or support staff, they do decrease the chances of harm to others.
- Service providers struggle to identify funding to provide for the cost of serving those with exceptional support needs related to extreme aggressive behaviors. Access to additional funding is difficult if not impossible to obtain and will not cover costs for more intensive support needs. One nonprofit provider described an example of an individual whose services were reimbursed at roughly one-half the actual cost over a four-month period, forcing the provider to use its reserve funds. If annualized, the cost of providing that level of support would exceed reimbursement by approximately \$70,000 for the individual.
- Lack of understanding about the origin of the behaviors of a person with developmental disabilities creates uncertainty about the appropriateness of typical community safety interventions. Law enforcement, for example, sometimes determines the person did not have the capability to formulate intent to commit a crime. In those cases the individual is not arrested and does not receive typical consequences incurred by people without disabilities. While the lack of intent is an accurate assessment in some cases, an inability to access support from public safety resources for those individuals means that community service providers inherit the roles of crime prevention and implementation of consequences.

- Because the pool of available support staff is limited, diverting more staff to clients with extreme aggressive behaviors means the level of staffing available to support other clients will decrease. This trickle-down effect decreases community inclusion, skill acquisition, and successful community inclusion for a wider group than those being studied by the Task Force.

3. When the behaviors of an individual rise to a crisis level, there are limited programs and services available to quickly resolve the crisis. Inpatient psychiatric care is commonly denied to individuals with developmental disabilities both by community programs and state hospitals, especially if the individuals have a history of violent or aggressive behavior.

- Numerous stakeholders have reported an inability to access inpatient psychiatric hospitalization for individuals with developmental disabilities who may be difficult to serve in any way.
- Concern about being paid for services is a major barrier to providing in-patient psychiatric care to this population.
- Those who seek crisis intervention services for this population indicate that they do not find the type of help they need to de-escalate situations where an individual is out of control and creating a risk of harm to others.
- Few mental health programs have been developed to address the needs of individuals who also have a severe cognitive disability and typical therapy models are not designed for this population.
- Calling for assistance from law enforcement whose response options are very limited, has become the fallback crisis resolution plan for individuals in this population.
- Families indicate that they have had to give up custody of their children to the State so that their children could receive the type of intensive supports required to keep them and others safe.

4. State policy is very prescriptive about the people that providers hire, but not those receiving supports. Community DD providers are very cautious to prevent hiring individuals with histories that may indicate the potential for harming clients, however those providers cannot be as selective to avoid serving clients who can harm other clients.

- Providers are expected to serve individuals who qualify for DD services, even if the individuals have a history of physical or sexual

abuse toward others. This expectation creates opportunities where those who victimize have access to those who are most vulnerable.

- State regulations are specific about disqualifying individuals from working in the DD service system if they have a known prior history of abuse against children or individuals who are vulnerable. The same standards do not extend to program clients.
- Access to public and private intermediate care facility services (residential facilities or state hospitals for people with mental retardation) is very limited. Due to the difficulty in accessing such service options, community service providers (CSPs) continue to serve individuals beyond a point that ensures the safety of the individual, other clients, staff and community members. Allowing these placements to continue as they currently take place creates a high likelihood that someone may be seriously injured or killed.

5. Key areas of the Sedgwick County community lack adequate, specialized services and policies to meet the needs of this population.

- Law enforcement officers, public defenders, prosecutors and judges look to community DD programs to provide alternatives to incarceration, as individuals with severe cognitive disabilities create complications for typical system processes.
- Law enforcement officers are required to make difficult decisions concerning the best interests of individuals in this population. Taking individuals into custody may not be the best course of action if the individual's health and safety cannot be assured while he or she is detained.
- Professionals in law enforcement, criminal justice and social services, including DD support professionals, typically do not receive sufficient training about people with DD. This may prevent the professionals from making a good determination about how to hold the person accountable.
- There is currently no community setting where individuals can be assessed to determine what level of support they will require in the community to be successful and ensure the safety of all.

6. Parents, guardians and professionals associated with DD services are not fully informed about accessing available community mental health services

- A memorandum of understanding between the DD and MH service systems gives primary responsibility for service coordination to the

DD system. If the developmental disability is not the primary issue, it may not be productive to expect the DD system to take the lead in coordinating supports and services.²

7. Local organizations place their reputation, financial stability and future existence at risk when they accept clients who may prove too difficult to support safely in the community.

- Accepting clients who are difficult to support safely creates an ongoing threat of incidents that are beyond the control of the provider and that can seriously harm its reputation for quality services.
- Supporting those who are physically violent increases costs for various types of insurance, including workers compensation.
- Hazardous work makes employee recruitment more difficult.
- An attorney advised a local community service provider that the extent of financial liability for an event where someone is seriously harmed or killed could be sufficient to close the organization's doors.

VI. Recommendations

The Task Force offers two types of recommendations to the Board of County Commissioners (BoCC) to address various dimensions to the problem as identified previously in this report:

1. Recommendations that can be accomplished through actions directed solely by the BoCC;
2. Recommendations that can be accomplished by governmental partners and for which the BoCC should advocate;

Recommendations that can be implemented or initiated by Sedgwick County:

- 1. Create a safe community setting dedicated for temporary placement of persons whose extreme aggressive behaviors cannot be managed in their current community placement.**

Some individuals require an enhanced level of support sporadically due to behaviors that may occur from time to time. While it may be possible to address those times with supports in the person's current setting, other situations occur when the individual would be better served to relocate to

² Department of Social and Rehabilitation Services 1998 program instructional memorandum

a setting that is better equipped to meet his or her needs. The goal of such a setting would be as a temporary location to allow time and provide supports so that the individual's behaviors can stabilize. The individual would return to his or her home or community program once the extreme aggressive behaviors are being appropriately managed.

- 2. Create a specialized, multidisciplinary crisis response team to respond to emergency circumstances in which staff members of community service providers are not able to successfully manage behaviors that are threatening to the safety of persons served, staff or others in the community.**

Some individuals can be supported successfully for weeks or months between incidents where they engage in extreme aggressive behaviors. Because of this, it may not make sense to excessively restrict the type of services they receive but rather to create a process to lend assistance when required. The creation of an intervention team, either from new or existing community professionals, would allow individuals to pursue the maximum level of community inclusion when behaviors do not limit their capability to do so. During periods when their behaviors do become more difficult to manage, a team of trained individuals representing appropriate service systems would respond to either lend guidance to the individual's support staff or to work in partnership with them to implement immediate and appropriate behavioral interventions. While there is presently some limited capability to share staff resources between community providers, there is no funding or reliable system in place to ensure that this type of support is available when it is most needed. Funding targeted specifically at this need would allow current providers the flexibility to pursue program development.

- 3. Contract with specialized service providers to develop the resources, facilities and proven expertise to provide services designed for persons with developmental disabilities who demonstrate extreme aggressive behaviors that make them too dangerous to serve in existing community programs.**

While providers of developmental disabilities services do indicate a good track record of meeting the support needs of most individuals with dual diagnoses, they also indicated a difficulty in meeting the needs of those who demonstrate extreme aggressive behaviors. Actions of people who demonstrate those behaviors can have an immediate detrimental effect on the ability to effectively support other individuals with disabilities. One solution to this issue would be to identify and contract with one or more providers that specialize in meeting the needs of those who engage in these behaviors. Such providers could ensure the types of facilities and level of staffing that would be required to safely support individuals who cannot be served in typical community programs. We emphasize there would be additional cost related to such a specialized support program to allow the provider or providers to create the infrastructure necessary for

this type of support. (Because this approach could limit the consumer's choice of providers, it may be necessary to receive authorization from the State to implement this recommendation.)

4. Establish a county policy that prohibits placement of persons with DD who have a known history of extreme violence or sexual aggression in close proximity to individuals who have limited capability to protect themselves.

In brief, state regulations require providers to do everything in their power to prevent hiring individuals who have a previous history of abuse or crimes against vulnerable individuals. While we understand and support such requirements, it does not make sense that there is a lack of recognition that people receiving services may also have a history of abuse or crimes against persons. Because of this, other clients receiving services may become targets or unintended victims of those around them who exhibit extreme aggressive behaviors. Risk from individuals receiving services should be considered as seriously as is risk from employees or prospective employees. Those with a history of harming others should be supported in segregated settings and in a fashion that prevents the chances of them causing harm to other persons receiving services.

5. Define circumstances that allow community providers to decline to serve any individual with DD who has a history of extreme aggression toward others.

Presently providers are required to serve all individuals who are referred to them, which may mean creating support settings that put the individual, other persons served, or direct-care staff at risk. This requirement has been implemented because the State presently requires the CDDO to serve all individuals who meet criteria for services. Because the CDDO does not provide these services, it must then pass this requirement on to performing providers. While the intent of the requirement is clearly to ensure that individuals are not discriminated against due to their disability or assigned reimbursement rate, it fails to take into consideration the few individuals who pose a great risk to themselves and the community. The CDDO should work with area providers and SRS to create a contractual basis that allows providers to decline to serve some individuals who cannot be served safely by community programs.

6. Beginning in 2007, and annually thereafter, provide leadership and resources for new specialized training for direct-care staff at area developmental disability agencies about how to safely and effectively work with individuals who engage in extreme aggressive behaviors that make them particularly difficult to support.

Because this is a very specialized population of individuals, it may not be realistic for each affected community service provider to obtain the type and level of training that is required by their direct-care professionals.

One possibility is that the CDDO can work in partnership with providers to contract for pertinent trainings and make those available to all local agencies that need assistance in accessing this training.

- 7. Beginning in 2007 and annually thereafter, create specialized training opportunities for first-responder professionals from public-safety agencies to expand their skills in meeting the needs of persons with developmental disabilities, especially those who engage in extreme aggressive behaviors.**

While community service providers and their staff are the first level of support for individuals who fall into this population, the nature of the behaviors exhibited does create situations where law enforcement, fire, ambulance service, and other systems are also required to respond. Determining the best way to meet the needs of these individuals can be particularly difficult for professionals who have no previous experience working with people who have a combination of developmental disabilities, mental illness, and extreme aggressive behaviors. Training should include a general background about individuals in this population and any current information regarding preferred practices for successful intervention and support.

- 8. Beginning in 2007 and annually thereafter, develop and provide annual cross-training to case managers in both the developmental disability and mental health systems in how to effectively work with persons who have a dual diagnosis or extreme aggressive behaviors.**

Case managers are responsible for coordinating supports required by their clients to allow them to be as independent as possible in their home community. While the case manager's knowledge about the system he or she works in may be very good, we found that there is a general lack of understanding about the capabilities and services of other support systems. Previous efforts intended to expand the knowledge of case managers about other systems should be built upon to ensure that those who require significant supports from both the developmental disabilities and mental health systems can access them. Effectively accessing the systems is necessary to help avoid extreme aggressive behaviors or the need for hospitalization or other restrictive interventions.

- 9. Beginning in 2007 and annually thereafter, develop and provide annual cross training to agency staff in the developmental disability, mental health, child welfare and aging systems to expand knowledge between systems.**

We discovered early in our learning process that lack of understanding between service systems does exacerbate problems related to meeting the needs of these individuals. An annual process that allows stakeholders from these systems and others to learn more about each

other's services and capabilities will lead to better coordination of existing resources. As was demonstrated in a case presented by a local provider of developmental disability services, systems can be working on behalf of an affected individual and not even know that other systems are also involved. There are also examples of stakeholders having expectations from systems in excess of what they can actually provide.

10. Expand the role of the CDDO as an information gatekeeper to assure a more accurate and complete transition to adult services for children with a history of violence or other challenging behaviors.

Providers have indicated that they sometimes receive referrals for services without having all necessary information about the individual, which can lead to inappropriate decisions about supporting her or him safely. The CDDO should play a stronger role in ensuring that all pertinent information about these individuals is made available to the chosen service provider before services are implemented. While this could delay some services from being initiated, it is hoped that it will more commonly result in more timely and complete disclosure by those who have met the support needs of the children prior to the transition process to adult services.

11. Create and fund a position in Sedgwick County with the responsibility to enhance communication between the mental health and developmental disabilities systems in responding to the needs of persons who require services and supports from both.

Cases where the two service systems did not do a good job of coordinating with each other lead us to recommend creation of a position that will have the responsibility for ensuring appropriate coordination and communication between systems. Communication issues are sometimes related to the failure of a key stakeholder to initiate appropriate communication, but at other times are related to requirements concerning the appropriateness to share information between systems. A coordinating staff member would have ready access to information from both systems and could quickly identify areas where important facts are not being communicated. This position would also create an independent perspective that is not driven by the constraints of either system, but rather upon the capabilities of the systems to meet the specific needs of the individual. We suggest that such a position could coordinate the crisis response team previously recommended or assist in coordinating services with the child welfare system and other stakeholders.

Recommendations that must be implemented by the State of Kansas:

- A. Ensure timely access to funding in excess of the typical state reimbursement rate that is sufficient to provide for the costly, specialized community services for persons with extreme aggressive behaviors.**

Serving these individuals is commonly a very costly endeavor, sometimes requiring more than twice the assigned reimbursement rate due to the number of staff who are required. Funding must cover the cost of services provided so that organizations that provide the services do not have to sacrifice the integrity of programs for everyone else they serve. There is currently an assessment process to determine if an individual qualifies for funding in excess of the typical reimbursement rates. Unfortunately this process has significant restrictions in terms of the level of funding that will be paid and how quickly the funding can be accessed. Those barriers must be overcome to ensure that community service providers that are responsible for meeting the support needs of individuals with extreme aggressive behaviors have sufficient financial resources to allow them to do that immediately.

- B. Expand the skills and tenure of direct care staff in community agencies by increasing state reimbursement rates to support higher levels of staff compensation.**

One recurring theme during the deliberations of the task force was that direct-care professionals simply are not compensated at a level that corresponds with the level of personal risk they are incurring in meeting the support needs of this population. While there are general concerns by community service providers about the adequacy of reimbursement rates for all individuals who receive community support services, this population creates special challenges in compensating staff for the intensity of work they must engage in and the potential that they may be harmed while performing that work. It takes a very dedicated individual to accept the terms of this work for \$8 or \$9 per hour when he or she can make comparable or better wages in a wide array of jobs that do not put them at risk of harm. Reimbursement rates must take these factors into consideration and allow providers sufficient revenue to appropriately compensate their staff for the important work they perform. We seek a future that allows more staff to make this work their career choice, rather than simply another temporary job.

- C. Ensure sufficient capacity at state mental retardation hospitals to respond to emergent needs of persons with extreme aggressive behaviors who cannot be served safely in the community.**

Task Force members do not recommend stepping back in time to the years when anyone who did not seem to be a good fit for the community

was sent to an institution. We do understand that the two remaining state hospitals for mental retardation have specialized capabilities and resources that give them an advantage in meeting the needs of individuals with these types of extreme aggressive behaviors. Parsons State Hospital, for example, has a ground-breaking program that works with individuals with a history of sexually inappropriate behavior. State hospitals should provide an immediate safety net for individuals who cannot be served safely in the community, but should not be viewed as a long-term residential option for most individuals. Hospital resources should also be made available as needed to assist in the assessment of an individual's support needs and evaluation of medical and psychiatric support needs.

D. The Board of County Commissioners should seek specific clarification from the SRS Secretary concerning the requirements to determine that a person cannot be served safely in the community.

State law indicates that only the SRS Secretary has the authority to determine if someone is not appropriate for community services. No examples were discovered where the Secretary had declared someone inappropriate for community services and such requests appear to be uncommon. This may be due to the current environment that leans heavily toward community supports rather than hospitalization in nearly every case. The Secretary needs to be receptive to information provided by CDDOs and community service providers when they believe they cannot safely meet the support needs of an individual due to extreme aggressive behaviors or a prior history of harming others. In situations when it appears an individual does create a serious risk of harm to himself or others, the Secretary needs to identify a more appropriate support model that will better meet the needs of the individual than is possible given the constraints of the community support system.

E. Expand specialized behavioral intervention for all children under age five who qualify for developmental disability services.

The SRS Secretary is once again requesting state funding for the coming fiscal year that would create a pilot program intended to provide early intervention services for children diagnosed with autism. The Task Force supports this initiative, but recommends that a wider group of children be targeted for early intervention services in an effort to minimize the development of unmanageable behaviors and the general need for lifelong support services. While early intervention is not a solution for every individual, it does create an opportunity for minimizing the effects of an individual's disability for many people with developmental disabilities. This ultimately reduces the need for intensive community supports throughout the person's life.

F. Create a viable, short-term process by which individuals with developmental disabilities who require immediate intervention to

ensure their safety can be hospitalized or required to receive specialized supports even in cases where they do not consent.

One barrier to accessing appropriate services is the ability of individuals who are their own guardians to reject those services, even when they may be endangering themselves or others. While guardianship is a legal process that should not be changed without thoughtful consideration, there are a small number of individuals who do not make good choices on their own behalf when they are in crisis and may be harmed as a result of those choices. More tools must be created that allow choices to be made on behalf of these individuals when the situation requires, while simultaneously safeguarding their rights.

G. Require by state contract that child placing agencies provide accurate and complete records when children who have been supported by the child welfare system transition to adult DD services.

As indicated in recommendation 11 above, the inability to access accurate and complete records for an individual can affect the ability of a community service provider to effectively meet the needs of that individual and to protect the safety of others. SRS should include in its contracts a requirement that contracting providers must provide complete and accurate records to partnering service systems when children transition into other programs. There should also be a provision that lists penalties when this requirement is not met.

H. Consider amendments to 1998 Program Instruction Manual to allow for more direction in how developmental disability and mental health agencies will work together.

Since its creation by the state in 1998, the instruction manual on coordinating mental health and DD services has been cited as a basis for how the support needs of an individual with a dual diagnosis will be addressed. Unfortunately the intent of that document did not carry forward through the years and now fails to appropriately address the growing complexity of meeting the community support needs of individuals who would benefit from services from both the developmental disabilities and mental health systems. The document was reviewed during the past few years to determine its sufficiency for the current service environment. The outcomes of that review process need to be utilized to ensure that state policy concerning coordination between the two systems is designed to create optimal outcomes.

VII. List of Task Force members

Bruce Brown	Wichita Area Department of Social and Rehabilitation Services
Robert Burns	Sedgwick County Sheriff's Department
Lois Clendening	Via Christi-St. Francis
Marla Flentje	Parent and Provider Board Member
Carla Lehr	Prairie View
Ron Pasmore	KETCH
Tom Pletcher	COMCARE of Sedgwick County
Sarah Robinson	Wichita Children's Home
Ben Sciortino	Board of Sedgwick County Commissioners
Lucy Shifton	Parent and Mental Health Advisory Board Member
Judy Stengel	Parent
Greg Sullivan	Parent and Physical and Developmental Disabilities Advisory Board Member

VIII. Acknowledgements

We gratefully acknowledge the leadership and support from the Sedgwick County Board of County Commissioners in contributing to the quality of life of persons in our community who have developmental disabilities. We also commend the Board and County Manager, Bill Buchanan, for their foresight in creating the Task Force to determine whether adjustments in services are necessary to enhance the welfare and safety of all persons with developmental disabilities, as well as the agency staff who work with them.

The Task Force could not have performed its work without the support and contributions of many other persons in the community and in state government. First and most importantly, we are grateful for the expertise and strong guidance the Task Force received from Sedgwick County's exceptional staff:

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Colin McKenney, CDDO Director
Amanda Pankratz, Management Intern, Sedgwick County Manager's Office
Chad VonAhnen, Sedgwick County Director of Community Relations
Kristi Zukovich, Sedgwick County Director of Communications

Other individuals who provided valuable information and perspectives:

People with disabilities and their family members
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Vonda Bankston, The Arc of Sedgwick County
Jan Blevins, Arrowhead West
Heather Borsdorf, Sedgwick County CDDO
Wendy Duhn, KETCH
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Captain Glenn Kurtz, Sedgwick County Adult Local Detention Facility
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Adena McCowan, Rainbows United
Lorie Metz, The Arc of Sedgwick County/Individual Advocacy
Carolyn Risley-Hill, Starkey, Inc.
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Margaret Zillinger, Director, SRS Community Supports and Services