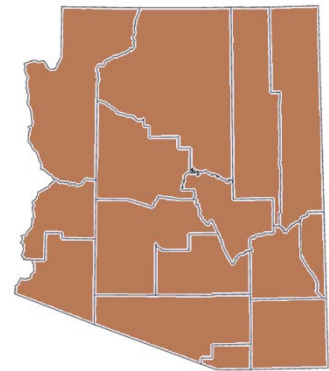


ARIZONA HUMAN RIGHTS COMMITTEE

Division of Developmental Disabilities

2016 ANNUAL REPORT



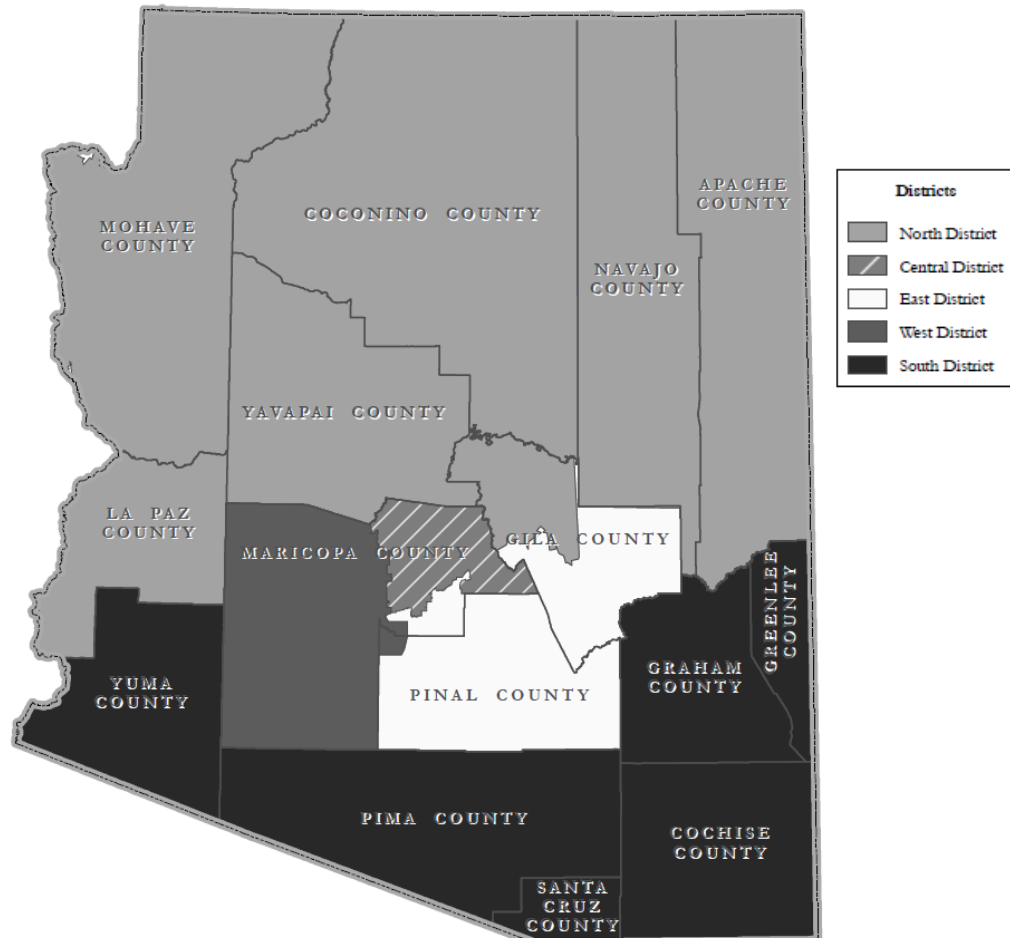
Arizona Department of Economic Security

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Geographical Composition by County and Chairperson

- District Central: Maricopa County (Central Area)
Chairperson (Phoenix): Karen Van Epps
- District East: Maricopa (East Area), Gila, and Pinal Counties
Chairperson (Mesa): Suzanne Kensington
- District West: Maricopa County (West Area)
Chairperson: Mona Zucker
- District South: Pima Cochise, Graham, Greenlee, and Santa Cruz Counties
and Yuma Counties
Chairperson (Tucson): Lynda Stites
- District North: Coconino, Apache, and Navajo Counties
Chairperson (Flagstaff): Cynthia McKinnon
- Yavapai, Gila (Northern Area), Mohave, and La Paz Counties
Chairperson (Prescott): Valerie Meads



Human Rights Committees

Human Rights Committees (HRC), also known as Committee, are required by A.R.S. §41-3801 and A.R.S. §41-3804 to act as an independent advisory and oversight for the Division of Developmental Disabilities (DDD) and the people they serve. The Human Rights Committee ensures the rights of clients are protected by reviewing incidents of possible abuse, neglect, and denial of rights. Each Committee meets at least quarterly each calendar year. However, Committees generally meet more frequently. The Committee is comprised of at least seven and not more than fifteen members. Members will have expertise in at least one of the following areas of psychology, law, medicine, education, special education, social work, criminal justice, and shall include at least two parents of children who receive services from the Division of Developmental Disabilities. Each District Committee also has a Chairperson attend the statewide HRC quarterly meetings to review and discuss individual issues and practices that may have statewide impact. The meetings also serve as a venue to improve communications among local Committees, identify statewide issues, recommend solutions to the identified concerns, and foster the discussion and resolution of issues between the Committees and the Division's Administration. The meetings afford the Chairpersons the opportunity to compare notes and help each other to improve their operations and to evaluate and plan for consistency in operations, thus elevating the level of awareness of human rights issues at the State level.

Human Rights Committee Annual Report

The Committee issues an annual report as noted in the Statute. Each Committee shall issue an annual report of its activities and recommendations for changes. The purpose HRC Committees pay particular attention to incidents they review to determine if there are any trends that need to be brought to the attention of the Assistant Director. The annual report goes to the DDD Assistant Director, the DES Director, the president of the senate, the speaker of the house of representatives and the Chairpersons of the senate health and human services Committee and the House of Representatives Health Committee, or their successor Committees.

Committee Responsibilities and Activities Performed

The significant function of the HRC is to review incidents of possible abuse, neglect, and denial of rights. Monthly, the HRC reviews all incident reports in their District from the previous month. The HRC evaluates the incident to determine if there is any human rights violations. The HRC can ask the Division to obtain further information for clarification. That information may result in recommendation for the Division and/or provider agency. HRCs receive incident reports from their District's quality management department. Based on a review of an Incident Report, the HRC may request Quality Assurance arrange an unannounced visit to a Division funded setting.

The Committees review Behavior Plans for individuals with developmental disabilities and make recommendations to Division staff when the Behavior Plan

interferes with individual rights for persons residing in State funded residential programs. The situation may or may not infringe on the individual's rights, but may nevertheless be at odds with the principles of self-determination, independence, or with issues related to least restrictive environment considerations. Subsequent discussions from this independent oversight and free flow of ideas allows for a better understanding of the complex interactions between Behavior Plans and individual rights. Upon review of a Behavior Plan, the Committee may make recommendations to the Program Review Committee (PRC) about any possible human rights violations. HRCs receive Behavior Plans from their District's Program Review Committee.

The Committees have a responsibility to review research conducted in the field of developmental disabilities for clients served by the Division. The Division will report the findings to the Human Rights Committees when they become available to the public.

Who are the Human Rights Committee Members?

HRCs are comprised of volunteers who donate time to the Division and each of the districts. Each district HRC has a chairperson, vice-chairperson, guidelines, and functions under the Open Meeting Law. Although many professionals and paraprofessionals serve on the HRCs, frequently HRCs include parents and family members of individuals that are currently receiving services. Many HRC members have served for several years and in some instances decades. This longevity provides the committees with continuity, stability, and expertise. The HRCs are supported by the Division's HRC Statewide Coordinator and District-specific administrative staff, who provide professional and clerical support for their operations.

Recruitment and Training

The year 2016 was not as active as in previous years for recruitment of HRC committee members. The interested candidates have expressed their interest in-part to reading about the HRCs from the Human Rights Committees brochure.

The search for qualified individuals who are willing to serve as HRC members has historically been a challenge. In 2016 the Sierra Vista HRC was disbanded.

HRC Chairpersons and Division staffs agree that recruitment efforts should extend to the entire community served by the Districts, in order to ensure a broader representation. Realizing the cultural and ethnic diversity of Arizona, Chairpersons continue to focus on recruiting HRC volunteers who represent a diverse base from every county they represent. The inclusion of new volunteers, some with no history of involvement with people with developmental disabilities, has brought diversity and a flow of new ideas to the HRCs.

Technical Assistance to Families, Staff and Providers

HRCs provide technical help, as needed, to families, providers, and Division staff. In most cases, HRCs help to address areas of conflict within the ISP Team or Behavior Plans that may interfere with the individual rights of Division members. The situation may not infringe upon members' rights, but it may conflict with the principle of self-determination, independence, or least restrictive environment. Subsequent discussions and the free flow of ideas allow for a better understanding of the complex interactions between behavior plans and individual rights.

Research in the Field of Developmental Disabilities

HRCs are required by law to review and preapprove (or reject) any plan for developmental disabilities field research concerning Division members. The Division reports any research findings to the HRCs, prior to making them available to the public. During 2016, no research proposals were presented.

The Role of the Human Rights Committees in the Divisions Quality Assurance Program

Data analysis is critical to a Quality Assurance Program, the primary goal of which is the improvement of conditions and outcomes for Division members and their families. In all Districts, HRCs and the Division's Quality Assurance Program work together on issues (e.g. abuse, neglect, and exploitation) concerning member rights.

Annually, District HRC Chairpersons and HRC Liaisons attend a meeting of the Statewide Quality Management Committee (SQMC) to present their annual report. The report includes an update on the District HRCs' activities and emerging issues/trends affecting their communities. The SQMC develops its annual goals, in part, to address the recommendations identified by the Statewide HRC Chairpersons' Annual Report, which is compiled from the individual annual reports of District HRCs.

HRC Statewide Coordinator

The HRC Statewide Coordinator and District staff will work with each of the HRC in their appropriate Districts, and will continue to provide clerical support to each of the six (6) HRCs across the state. The Division has hired three HRC Liaisons for the purpose of providing clerical support to the HRCs statewide under the guidance and supervision of the Human Rights Statewide Coordinator.

District West Human Rights Committee 2016 Annual Report Maricopa County (West Area)

INTRODUCTION AND BACKGROUND:

Human Rights Committees, supported by the Arizona Department of Economic Security, were established into law under A.R.S. 41-3801 and functions as an independent advisory and oversight committee to the Division of Developmental Disabilities. Human Rights Committees were established to promote and protect the rights of members with developmental disabilities who receive services from the Division of Developmental Disabilities.

District West is located on the west side of Maricopa County and extends south including portions of the Gila River Indian Reservation, to North Phoenix, and West to the border of Arizona. In 2016 District West served approximately 8,000 members.

RESPONSIBILITIES AND DUTIES OF THE HUMAN RIGHTS COMMITTEES:

The Human Rights Committees are made up of dedicated volunteers, who donate their time to serve the members within their districts. The HRC operates under the Open Meeting Laws of Arizona, and follows specific HRC By-Laws created by their district. The District West Committee meets approximately ten times per year. The Chairman and members attend and participate in the Quarterly Statewide Meetings. The Chairman and other HRC members, also attend other various public, state, and community meetings.

The committee provides independent oversight, review, research and also makes recommendations to the Department of Developmental Disabilities. The committee reviews incidents of Abuse and Neglect, Emergency Measures, Human Rights Violations and Death. The committee members also review Behavior Treatment Plans (BTPs) and make recommendations for change.

DISTRICT WEST HUMAN RIGHTS COMMITTEE

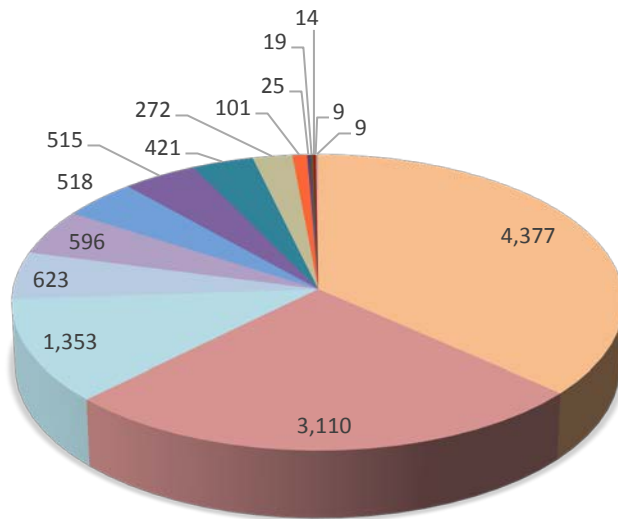
The District West Human Rights Committee (HRC) is comprised of dedicated community members including parents, family members, professionals, and paraprofessionals who volunteer their time and knowledge to advocate for DDD members. Active members for the year of 2016 include: Mona Zucker (Chairman), Pat Thundercloud (Vice Chairman), Emily Taylor, Eileen Rossback and Philip DeVico.

2016 ACTIVITIES

ADVOCACY:

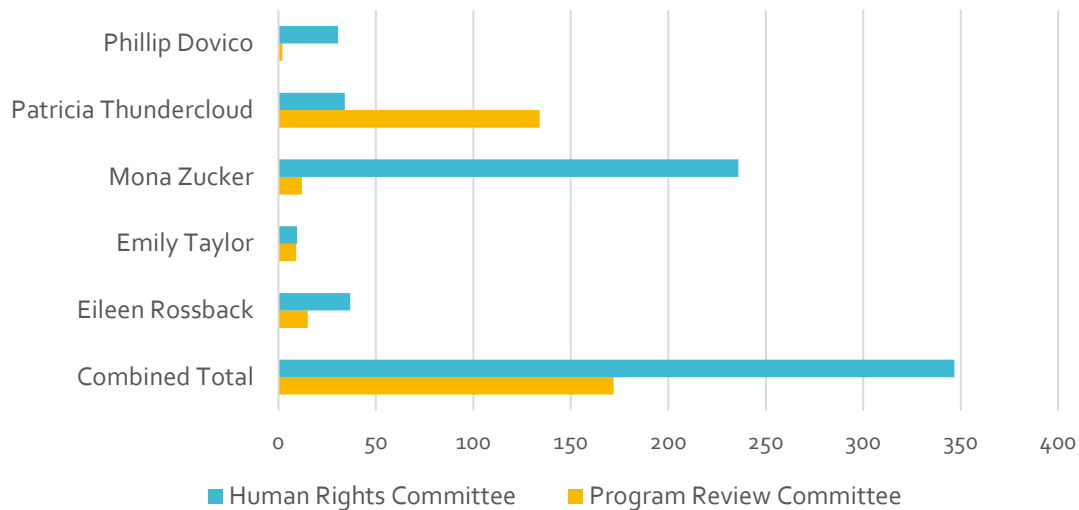
The District West Chairman(s) advocated for the rights of its members, parents, and guardians, by attending ISP's, BTP's, IEP's and other meetings to support the members and families and their best interests. This year the committee helped a family obtain eligibility after a year-long struggle. In addition, the District West HRC has taught many of its members and families how to advocate for themselves and their family members.

Services for Members District West 2016



- Respite Hourly RSP- Respite, Hourly
- Habilitation Hourly HAH- Habilitation, Home-Based
- Attendant Care ATC- Attendant Care
- Attendant Care RRB- Room and Board, All Group Homes
- Attendant Care HAB- Habilitation, Group Home
- Respite Daily RSD- Respite, Daily
- Residential Daily RBD- Room and Board, Vendor Supported Developmental Home
- Residential Daily HBA- Habilitation, Vendor Supported Developmental Home
- Residential Daily HAM- Habilitation with Music Therapy
- Residential Daily HBC- Habilitation, Vendor Supported Developmental Home (Child)
- Residential Daily HID- Habilitation, Individually Designed Living Arrangement
- Habilitation Nursing HAN- Habilitation, Nursing Supported Group Home
- Habilitation Nursing HAI- Habilitation, Individually Designed Living Arrangement
- Habilitation Daily HAA
- Habilitation Daily RBS

Member Volunteer Hours for 2016



RECRUITMENT AND TRAINING:

Recruitment continues to be an ongoing issue for District West. No additional members were appointed in 2016. In May of 2016, the committee members took Article 9 Prevention and Support Training taught by Timothy Payne and became certified in Article 9.

SPECIAL ACHEIVEMENTS:

In August 2016, District West Members Phillip DoVico and Eileen Rossback received a Certificate of Achievement Award from the DES/DDD Volunteer Services Department for volunteering on the committee.

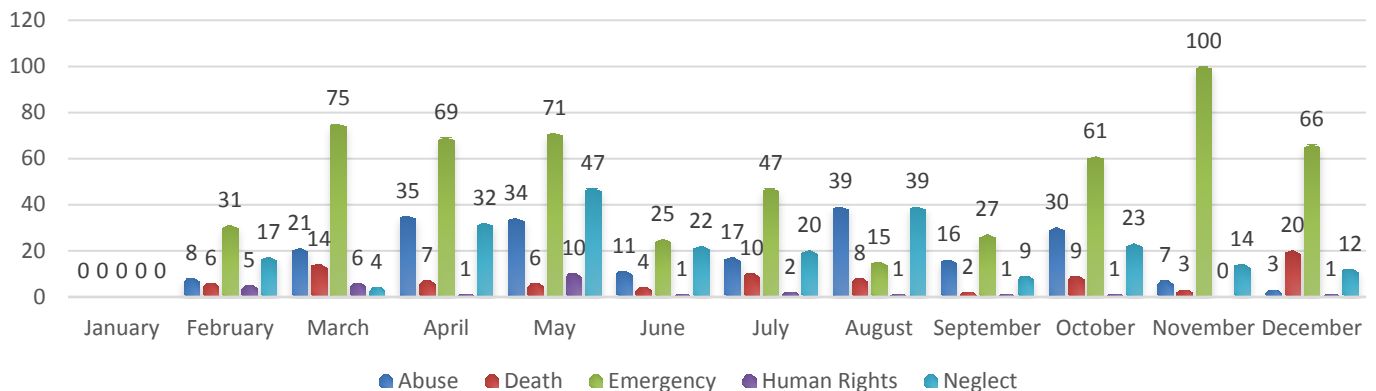
ISSUES:

The District West Chairman met with Tim Jeffries, DES Director, Dr. Laura Love, DDD Assistant Director and Lisa Cavazos-Barrett, DDD Assistant Deputy Director and District Central HRC Members to discuss ongoing issues within the committee. Creating Guidelines for the HRC was discussed. This is yet to occur.

INCIDENT REPORTS

District West received a total of 1,207 Incident Reports for approximately 8,873 members. This is a significant increase from 2015, when District West received 426 Incident Reports for approximately 8,100. In November and December of 2015, District West HRC received ZERO Incident Reports for its members, due to a Division redaction issue. For most of 2016, the committee only received closed incident reports. Given the number of members in District West, the committee believes it should receive more Incident Reports. The committee is not receiving every type of Incident Report requested, including Physical Abuse, Sexual Abuse and Other Abuse, Neglect, Accidental Injury, Missing Clients, Emergency Measures, Human Rights Violations, Medication Errors, Death, Suicide, Hospitalization, and Legal. In addition, not receiving or having access to both open and closed Incident Reports regarding DDD members is a violation of their human rights. The HRC Chairman did not receive any death notifications within 24 hours in 2016, as required in statute.

2016 Incident Reports



ADULT PROTECTIVE SERVICES (APS):

In 2016, District West struggled to obtain requested records from APS. This has been discussed at the Statewide HRC quarterly meetings. In addition, there are times when the investigation by APS is not done in a timely manner. There are four APS Investigators statewide who have to triage cases based on severity. It was discovered that APS closes any case that they are not able to prosecute, regardless if the incident occurred or not. This is a true disservice to DDD members that have been victimized. District West recommends that APS add a category for substantiated closed cases that they are unable to prosecute. Additional APS investigators are needed or the Division needs to add its own investigative unit, to ensure timely investigations.

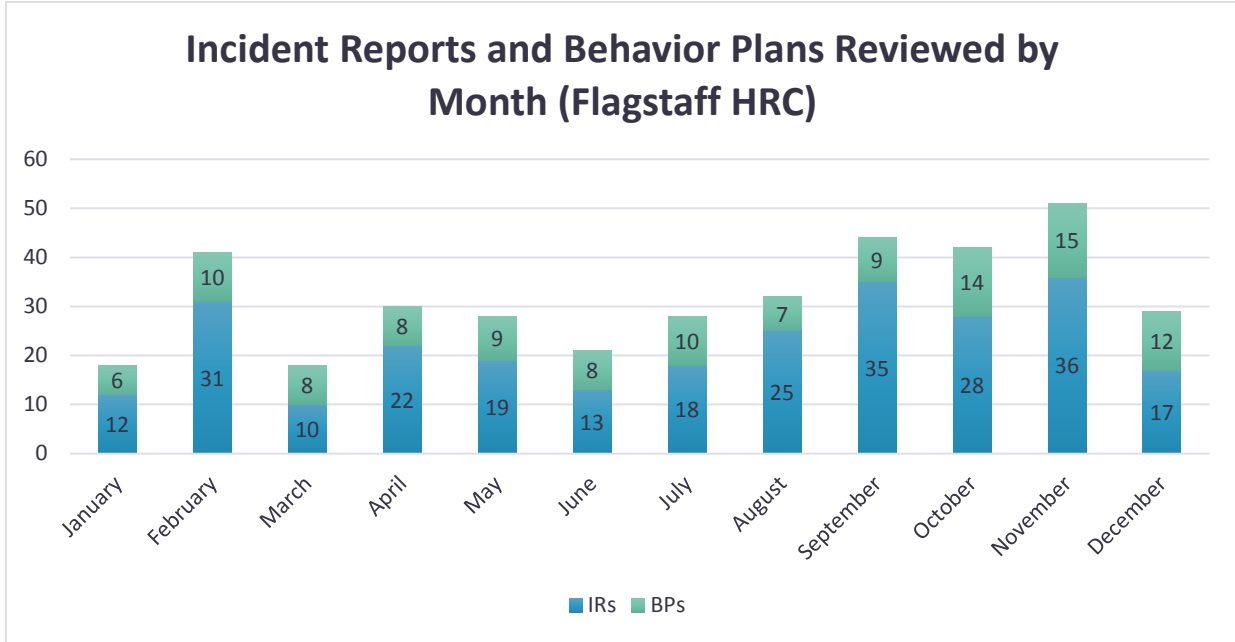
PROGRAM REVIEW COMMITTEE (PRC):

In 2016, District West PRC continues to be an issue for the District West HRC. HRC members are not allowed to sit on a PRC as an HRC member and therefore receive redacted BTP plans. HRC members attend as a parent or interested community member to participate and can then receive an unredacted plan. In other districts, the HRC members have been allowed to sit on their PRC as HRC members and receive unredacted plans. In District West the PRC is still not following policy and does not have the proper type of committee members sitting on their PRC per statute.

MEMBER CONCERNS:

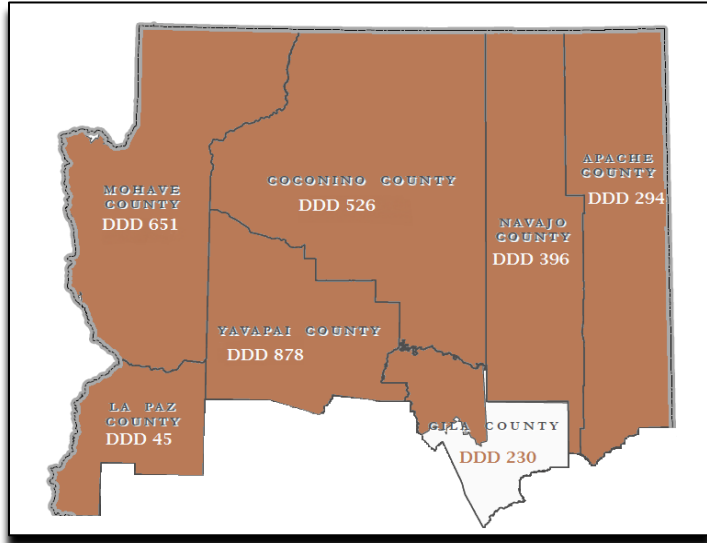
District West HRC has concerns regarding members' financial accounts, nursing homes, placement issues and administrative reviews. Many members' accounts balances are going over \$2,000 dollars despite having fiduciaries. This disqualifies from receiving Arizona Health Care Cost Containment System (AHCCCS) services and they lose their eligibility status. District West is concerned that Adult Developmental Homes (ADH) are not being monitored by the Division. The HRC receives many Incident Reports from the ADHs. Nursing Homes are not an appropriate placements for DDD members. There is a concern that DDD members are not monitored appropriately by the Division, have a poor quality of life and deteriorate rapidly. District West is also concerned that DDD members and families are not being given a choice of placement. There have been several complaints that choice is not offered by the Division. In addition, the family does not have access to the provider agency's performance. There are no vendor report cards available to DDD members or their families. The members and families must choose a provider agency without having enough information to make an informed decision. District West is concerned that Administrative Reviews are past due. The Division has 30 days to respond. In at least one case, the Division was 60 days past due with the Administrative Review.

District North (Flagstaff) Human Rights Committee 2016 Annual Report Coconino, Apache, and Navajo Counties



District North currently serves six counties in full and another one partially. During the 2016 year the Flagstaff HRC reviewed at total of 266 incident reports and a total of 116 behavior plans.

2016	IRs	BPs
January	12	6
February	31	10
March	10	8
April	22	8
May	19	9
June	13	8
July	18	10
August	25	7
September	35	9
October	28	14
November	36	15
December	17	12



ALTCS DDD Membership by County as of October 1st, 2016*
Stats provided by the AHCCCS ALTCS Enrollment Summary Report

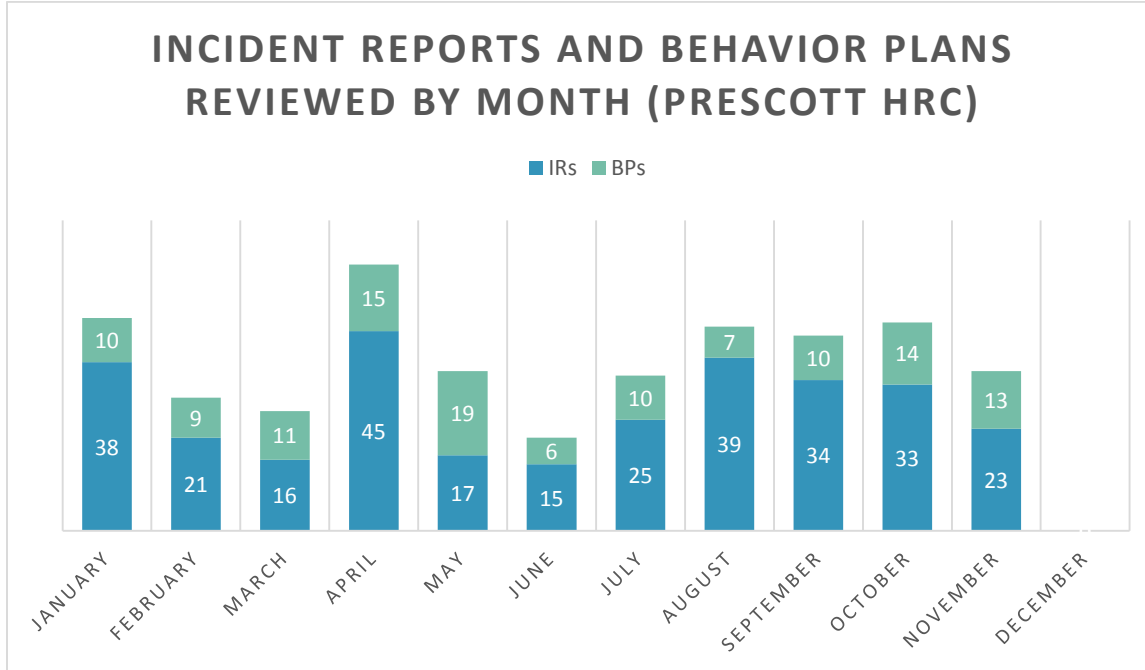
HRC Flagstaff Annual:

ISSUES:

1. The Committee suggests a step down unit be constructed in Coconino County to provide a safe and secure facility for clients who need medication changes, who are leaving other facilities (mental health, hospital, group homes, and jail) and need time to adjust, and for clients who are having a crisis.
2. The Committee finds chronically low wages and underfunding by the State of Arizona is having a negative impact on the quality of life of DDD liens resulting in difficulty in hiring and retaining appropriate staff. In Flagstaff, where an increase of minimum wage was instituted, qualified vendors are threatening to close their doors.
3. The Committee finds that DDD does not have a system to assure BTPs are current.
4. The Committee finds that providers are contacting police rather than running the plans designed to properly handle behaviors.
5. The Committee finds that providers, when consulting the CRISIS PLAN, are instructed to contact police thus arresting clients for the very behaviors addressed in their BTP's and finds that this is a HUMAN RIGHTS VIOLATION.
6. The Committee requests that dental care be provided DDD clients and that the barbaric practice of extraction rather than dental care be stopped.
7. Immediate and comprehensive action is needed to provide guardians for the DDD population as many individuals incapable of verbal communication, understanding language, and with severe MR are their own guardians. This places DDD and the State of Arizona in a legally perilous position.

**District North (Prescott)
Human Rights Committee
2016 Annual Report**

Yavapai, Mohave, LaPaz Counties and the Payson Area



2016	IRs	BPs
January	38	10
February	21	9
March	16	11
April	45	15
May	17	19
June	15	6
July	25	10
August	39	7
September	34	10
October	33	14
November	23	13
December	0	0

During the 2016 year the Prescott HRC reviewed at total of 306 incident reports and a total of 124 behavior plans. Activities: During 2016, the Prescott Area HRC met nearly every month and requested the District North DES PRC Chair and QA Manager, be in attendance at those meetings.

In January 2016, written HRC GUIDELINES were submitted to the DES DDD Central Office for approval pursuant to the provisions of ARS 41-3804A; no response to indicate DES Director approval of that submittal, nor to the "Recommendations" made in the 2015 (Annual) Report, have been received. Recommendations:

Resolution to above and to ongoing significant communications with the DES DDD Central Office, both of which affect the standard operating procedures of the District North HRC - Prescott Area.

INCIDENT TYPE	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Consumer Missing	5	-	2	3	2	4	7	3	2	1	1	-
Death	5	-	2	5	1	0	0	4	2	0	2	-
Emergency Measures	9	-	4	3	6	0	6	4	9	6	4	-
Human Rights Violation	5	-	1	5	3	2	2	2	6	4	3	-
Legal	3	-	2	2	0	1	0	6	1	5	2	-
Neglect	4	-	3	15	2	3	5	9	9	10	4	-
Other Abuse	4	-	1	4	3	2	2	8	4	5	5	-
Physical Abuse	3	-	1	8	0	3	3	3	1	2	2	-
TOTAL	38	21	16	45	17	15	25	39	34	33	23	-

**District South (Tucson)
Human Rights Committee
2016 Annual Report
Pima Cochise, Graham, Greenlee, and Santa Cruz Counties
and Yuma Counties**

INTRODUCTION AND BACKGROUND

It is a pleasure to submit our 2016 Annual Report for the Human Rights Committee (HRC) in Tucson with support to Sierra Vista and Yuma. Because there was no Human Rights committee operating in Yuma or Sierra Vista during this period, the Tucson committee reviewed all Incident Reports from those areas as well.

Human Rights Committees were established under ARS 41-3801 and function as independent advisory and oversight bodies across the State.

RESPONSIBILITIES OF THE HUMAN RIGHTS COMMITTEE

The Human Rights Committee of dedicated volunteers, in addition to providing independent oversight and review and making recommendations, functions under the Open Meeting Law and follows District-specific Bylaws. The Committee includes professionals and paraprofessionals, as well as interested parties.

SPECIFIC CHALLENGES

This calendar year brought several challenges to the basic functioning of the Tucson Human Rights Committee. As mentioned in last year's report, Behavior Treatment Plans continue to be inconsistent in structure and order and are difficult to read.

The Tucson committee feels that the lack of consistent quality and general unreadability of the BTPs represent real violations of human rights for members due to the inability of care givers and service providers to understand the plans. We would like to see a more consistent format for BTPs and the use of wording that is easily understood by all service providers.

The committee in Tucson has struggled to recruit and retain members. It now has 3 active members. A challenge encountered by such a small committee is that if one or more members is unable to attend a meeting the committee must decide about whether to hold a scheduled meeting or to try to reschedule. The committee had two incidents in 2016 where DDD staff cancelled its meetings: one occasion was because staff had difficulty arranging support in the form of providing the committee with necessary Incident Reports to review. That meeting was summarily cancelled the day of the meeting. In the instance of the second cancellation, DDD staff decided, in the absence of any prior communication with the committee, to cancel the scheduled meeting due to their belief that there would not be enough members in attendance to hold the meeting.

One challenge for the committee during 2016 was that, since meetings were scheduled from 4:30 to 6:30 pm and the DES building in which it was meeting was closed at 5:00, if an attendee arrived late for the meeting, he or she would be unable to access the meeting room. Due to this situation and the situation with previously cancelled meetings, the committee decided to move their meetings to the public meeting rooms at the Valencia Branch of the Pima County Public Library located at 202 W. Valencia in Tucson. It was decided that holding meetings in this more accessible location would be beneficial to both the committee and to the public who might be interested in attending the public portion of the meetings. The committee met at this location from July to December of 2016. Additionally, because of DDD staffing issues and turnover the committee decided to forego having staff support during our meetings, choosing to record its own minutes and reserving meeting rooms on its own. The committee requested that all Incident Reports and Behavior Treatment Plans be mailed to members in the week preceding the meetings so that members would have time to receive and review them. The process worked well for the committee for the remainder of the year.

The committee addressed questions regarding Incidents to Quality Assurance. These questions were handled by Pauline Selmer, who was thorough in explaining processes and results of Quality Assurance fact finding.

MEMBERSHIP

The Tucson Committee

The Tucson committee membership remained constant throughout the year.

The members include:

Lynda Stites (Chair)

Stacy Santos

Genevieve Valenzuela

DES Staff supporting the committee include:

Anzorena Fuentes (Clerical Support), until her resignation early in the year.

Barbara Carty, PRC Chair, provided clerical support until March, 2016.

Richard Kautz, Statewide HRC Liaison

The Sierra Vista Committee

RECRUITMENT AND TRAINING

Nancy Johnson, Volunteer Coordinator for the District, retired during 2016 and had not been replaced permanently by year end.

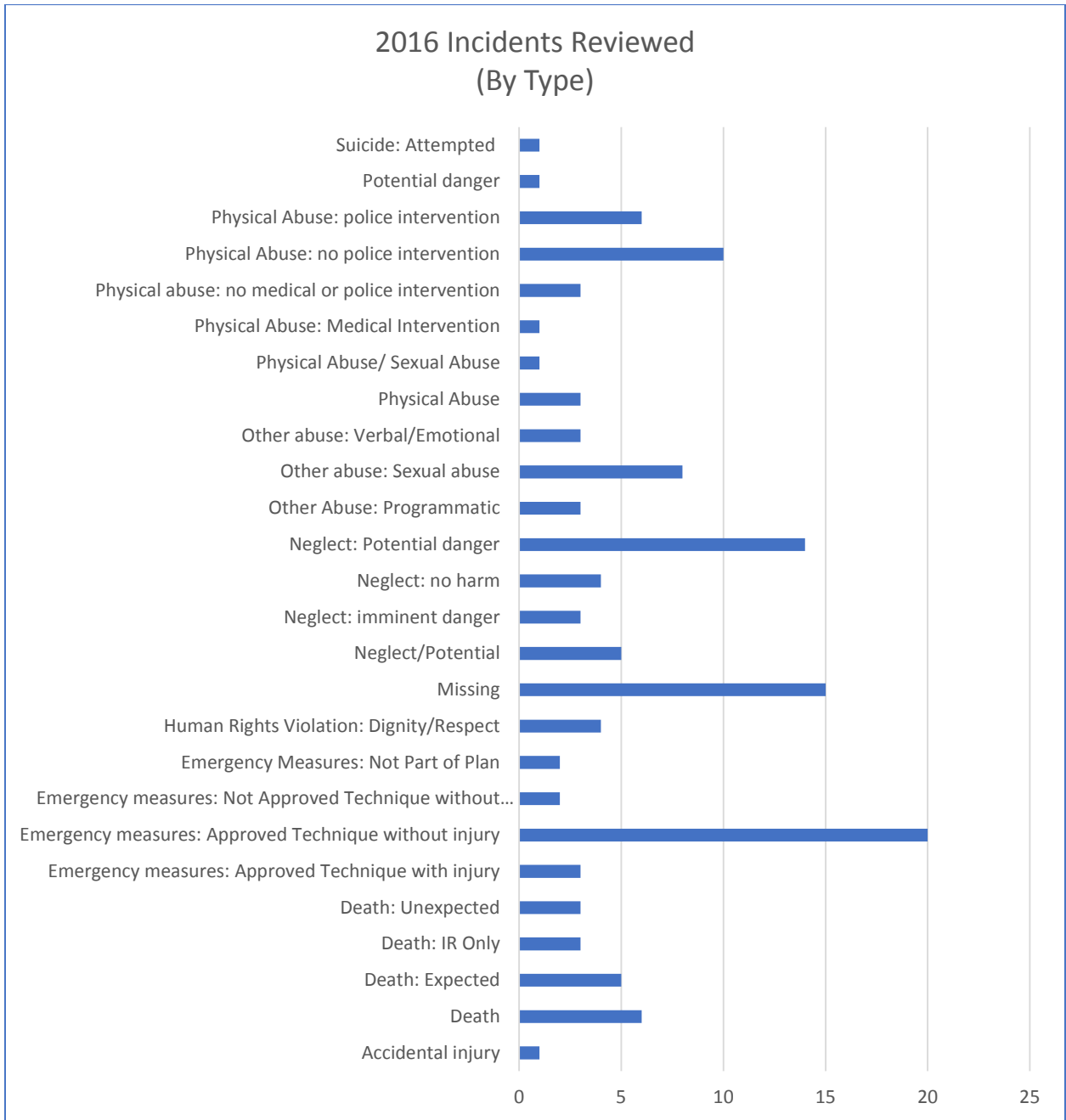
ORGANIZATIONAL STRUCTURE

The HRC's are groups of volunteers with DDD staff offering clerical support and providing the committee with Incident Reports to review and Behavior Treatment Plans to approve.

STATISTICS

	IR's Reviewed	BTPs Reviewed	Meetings Held	Volunteer Hours
Tucson	130	No record	8	145

** In Tucson, the hours counted do not include the variables of time spent reading plans.



OTHER ACTIVITIES

The District South committee has maintained a tracking system of all Incident Reports reviewed to track trends and agencies over time. When the committee

reviews Behavior Treatment Plans monthly, each member reviews several plans at home and then mails the approved or not-approved disposition form to PRC Chairperson, Barbara Carty. The review of BTPs has not been tracked by the committee, so there are no statistics for how many have been reviewed or approved by the committee for 2016.

This concludes the annual report of the Human Rights Committee, District South.

Respectfully submitted,

Lynda Stites

District South Human Rights Committee Chairperson

District Central Human Rights Committee 2016 Annual Report Maricopa County

HRC Committee Membership

Karen Van Epps, Chairperson; Family Member/Advocate
Carol McNulty, Vice-Chairperson; Family Member/Advocate
Maryann Germain; Parent
Eva Hamant; Parent/Advocate
Mandy Harman; Receives DDD Supports
Linda Mecham; Parent/Advocate
Andrea Potosky; Parent
Debbie Stapley; Parent
Lisa Witt; School Psychologist/Family Member
Euarda Yates; Parent

Volunteer Hours

The District Central HRC volunteered 964 hours during 2016.

Incident Reports

The HRC believes the person taking the initial call on an Incident Report (IR) should have a list of questions to ask the person reporting the incident.

The HRC would like to receive all IRs. The HRC recommends that IRs include precursors and antecedents.

HRC recommends the Division to have their own investigators instead of relying on the Department of Child Safety (DCS) and Adult Protective Services (APS).

Behavior Treatment Plans

The Division needs to adhere to the policy of Article 9 as it pertains to members required to be present during the Program Review Committee (PRC). A behavior specialist should always be present at each PRC. There is also a lack of vendors and support coordinators available for the PRC meetings. HRC recommends that the vendors should be required by contract to attend and participate in the PRC process. HRC recommends that the vendor send staff that work with the member.

If a member is on probation or a court ordered restriction, the HRC recommends that information be included in the Behavior Treatment Plan (BTP) and the Individual Service Plan (ISP).

Member Quality of Life Concerns

There are issues of members losing AHCCCS eligibility when they have over \$2,000 in their DDD account and DDD is the payee. This limit places a burden to spend the money for many individuals that receive a large amount due to SSA funding. There are some cases where guardian payees do not give their wards the money needed each month. This abuse of benefits needs to be reported to the Social Security Administration or the courts.

HRC is concerned about medication appointments being conducted over Skype with physician assistants in other states. HRC concerns focused on HIPAA issues and lack of personal interaction from the person conducting the interview on camera. The HRC believes given the millions of dollars AHCCCS pays for behavioral health our individuals are not getting quality care from impersonal Skype appointments. Nursing assessments should be done prior to a placement. These assessments should also be done face-to-face, not via telephonic or other remote methods. The HRC does not feel a "chart review" assessment is appropriate or serves the needs of our members. The HRC recommends that all medication appointments and nursing assessments be done in-person.

Placement and Monitoring Concerns

HRC is again concerned that Adult Developmental Homes (ADH) are not monitored by the Division. HRC is concerned about individual with high behavioral or medical needs being placed in ADHs without adequate support for caregivers.

DDD members should not be placed in nursing homes. DDD members have unique needs and these facilities are not able adequately meet those needs. In addition there are members diagnosed with significant behavioral issues yet DDD does not have appropriate residential settings to adequately address their needs. The HRC recommends that DDD develop appropriate residential settings for those with dual developmental and behavior diagnoses. The HRC further recommends that additional services and hiring of specialized behaviorally-trained staff be implemented.

Representatives of the parents and friends group of ATPC, the Arizona Training Program at Coolidge presented an overview of their concerns about the proposed closure of the group homes on the campus and the institution. The group fears that movement of the Members who have lived at the facility for most of their lives will have a negative impact and there was no realistic plan presented to move these Members. The Representatives met with Director Jeffries and Dr. Laura Love, but there was nothing further proposed to the group.

The usefulness of The Arc Monitoring has been questioned by the Human Rights Committees as it is currently being administered. The Contract refers to the necessity of at least 2 monitors at each visit. There has only been one. The Contract refers to The Arc Residential Committee that will review the monitoring. There is nothing that indicates this has happened. The Human Rights Committees, which are to receive the reports, have not been receiving them. Previously, Arc monitors were volunteers. Currently, DDD pays The Arc which negates the purpose of the outside oversight. Human Rights Committees would like for DDD to carefully review what The Arc contract demands. The concern is that this type of monitoring is just an "add-on" to the monitoring that DDD already does in Group Homes.

HUMAN RIGHTS COMMITTEE
DISTRICT EAST
2016 ANNUAL REPORT

Division of Developmental Disabilities

**Prepared by Suzanne Kensington Chairperson
on behalf of the Human Rights Committee District East**

Human Rights Committee Function

Human Rights Committees (HRCs) are required by ARS 41-3801 and 41-3804 and function as an independent advisory and oversight committee for members being served by the Arizona Division of Developmental Disabilities. District East serves the southeastern portion of Maricopa County, southern portion of Gila County and all of Pinal County, including the Arizona Training Program at Coolidge.

Each committee shall provide independent oversight to:

- Ensure that the rights of clients are protected.
- Review incidents of possible abuse, neglect or denial of a client's rights.
- Make recommendations to the appropriate department director and the legislature regarding laws, rules, policies, procedures and practices to ensure the protection of the rights of clients receiving behavioral health and developmental disability services.
- Each committee shall issue an annual report of its activities and recommendations for changes to the director of the appropriate department, the president of the senate, the speaker of the house of representatives, the chairpersons of the senate health and human services committee and the house of representatives' health committee, or their successor committees.

Our primary efforts have been focused on reviewing Incident Reports given to us by DDD Quality Assurance and Behavior Treatment Plans submitted to DDD, that have been approved by Program Review Committee for DDD, for individuals who live in a DDD residential setting and are taking any medication(s) that assist in behavior modification. In addition, we have advocated and counseled with individuals and their families.

Reports Requested to Review

We have requested to review the following reports which have not been delivered to our committee:

- Residential monitoring compliance reports and summaries of homes monitored in the area along with corrective action plans
- Reports of special investigations received by the Division
- Provider investigations, subsequent analysis of report findings, and corrective action plans
- Data and trend analysis compiled by the Division's Quality Assurance Program
- Incident Reports for every category

Membership

Suzanne Kensington – Chairperson – Parent/Advocate, Realtor

Jennifer Huot – Vice Chairperson – Special Education Teacher

Gina Johnson – Parent/Advocate, Founder of Sharing Down Syndrome

Leon Igras – Parent/ASU Safety Director

Sheri Reed – Parent/Special Education Teacher, PhD

Tammy Leeper – Parents/Nutritionist (Joined February)

Al Tijerina – Parent/Retired (Joined February/Resigned November)

Mary Lou Rangel – Parent/Nurse and Adjunct Faculty (Resigned in October)

Lisa Roberts – Parent/Nurse and Adjunct Faculty (Resigned in December)

Per ARS 41-3801 our committee is to be comprised of at least seven and no more than fifteen members with members having expertise in the following areas: psychology, law, medicine, education, special education, social work and at least two parents of children who receive services from DDD.

There was on-going confusion and issues regarding ATPC and their HRC committee. It was finally decided that all information necessary for a HRC to review would come to our committee. We invited any remaining members to join our committee, however they chose not to join with us.

Recruitment and retention is an ongoing issue. We had three members resign and two join in 2016. We had three more that turned in their paperwork and attended just a few meetings and never participated again. Each of our members share information about our committee to help further the recruitment process. To improve retention, it is important for our members to feel that the time they are giving is making a difference in improving the lives of our members, as it is a large time commitment. This can be better accomplished through more transparent communications from the Division regarding outcomes. To improve retention as a committee, we have worked hard to create organization, efficiency, good communication, training, easy access to information and group harmony. We believe that more support from the division with formal training would increase retention.

We provided training for Article 9 for our members in August. Tim Payne came to the Mesa location and taught a 3-hour class and tested our members. All who attended passed and received their certification.

Our committee is made up of individuals who are employed full time, primarily parents who have children receiving a variety of services from DDD and Behavioral Health. As such, we all bring insight from our experiences with the Division and the agencies providing services. Our diverse insight allows our committee to openly discuss differing points of view to come to a collective decision on matters before us. Dedicating the time necessary to participate on the committee has been a strain at times on our members as they also have had to handle issues experienced by their children served by the Division; however, they chose to serve in order to make a difference.

DDD Staff

2016 was a year in turmoil for the division. District East was without a District Program Manager from April through June and again August through December. Many high-level positions were fired leaving many positions vacant for extended periods of time. Administrative staff for our committee quit in May due to the chaos and lack of leadership. New temporary staff was hired but needed training and that left a lot of administrative duties on the chairperson. In December Director Jeffries was fired. In October, the PRC Chairperson position was filled. That position had been vacant for over a year.

In order to streamline administrative staff duties, as well as help our committee operate in the most efficient way possible, we have repeatedly requested a solution of some web based distribution. There are many available at little or no cost. DDD intranet or web based software program like Google Drive, Dropbox, OneDrive or Evernote are available. We haven't received any approval or support from DDD in those efforts. We created our own Dropbox where we have references, resources, training, agendas, past minutes and time sheets available for easy access. We are currently working on collaboration and communication regarding IRs and BTPs through Dropbox. What we are requesting is that BTPs and IRs to be distributed to us through this manner. This would give us the ability to refer back to previously reviewed BTPs to ensure requested changes were made and previously reviewed IRs to track ongoing issues with individuals or agencies. This would eliminate the need for administrative staff to redact and produce copies, reduce paper waste and eliminate the need to collect and shred documents.

Dedicated support coordinators who specialize in clients with high behavioral needs would allow them to have a more comprehensive knowledge of the resources and supports available to those clients and their families. Raising a child with special needs can be exhausting physically, mentally, emotionally and financially. Support Coordinators and families many times are not aware of what resources are available. Specialized SCs can help navigate the system to access those resources and bridge the gap between services offered by DDD and RBHA.

Incident Reporting Format

Our committee is only being provided a small number of the incident reports input in the system for our members. We are provided other abuse, physical abuse, neglect, emergency measures, human rights violations and death. We have requested to receive all of the reports; however, have been told that there is not adequate staff to redact the reports. The issue of redacting reports hampers our ability to provide the oversight the law requires.

The committee found that the current IRs do not provide enough information to form an opinion on what occurred. We need to have statistical and expanded information about these agencies, staff and clients to get the bigger picture. What was the antecedent? What was the precursor? Is there a guardian? Where do they reside? Is there a BTP in place? Is it working? Number of incidences regarding this client in the last 90 days? This information would allow us to make more informed recommendations to improve the quality of life. We also would like more information on specific actions that were taken regarding the IRs to protect our members and prevent further problems. Currently our reports show substantiated or unsubstantiated by APS or DCS but no report from those agencies. This leaves us wondering as to the depth of the investigation as in most cases the reports show unsubstantiated.

Direct Care Staff

Our committee found that the quality of life of our individuals is severely impacted by the lack of quality direct care staff, poor training of that staff and low wages. We read wonderfully written ISPs and BTPs only to find that they are not being read by agency providers and therefore not being followed. There is substantial failure on the part of many providers to properly train direct care staff. Providers complain that there is a shortage of quality workers.

The passing of the minimum wage law caused many issues for providers. Many smaller providers were not able to keep their businesses open. In some cases, larger agencies picked up the slack and in many more, members were left with no services.

Standardized mandatory behavioral training for direct care staff who care for clients with extensive behavioral needs require ongoing mandatory continuing education to be provided by Behavioral Health Specialists. This would help to minimize use of emergency measures, decrease escalation of behaviors resulting in verbal and physical aggression, property damage, self-abuse, crisis and police involvement. Workers having specialized training will be able to better implement behavioral treatment plans and therefore experience less behavioral issues from the members. This would create better employee retention and reduce training costs for agencies.

AHCCCS implemented Direct Care Working training and testing programs for workers providing in-home care services (attendant care, personal care and homemaker services). This program does not apply to licensed settings. This program would be a good start, however not comprehensive enough for working with members with extensive behavioral needs.

There is an overall theme seen both in BTPs and IRs regarding members wanting to be respected by not being rushed, not being spoken to like a child, not having power struggles with staff, not saying no and not giving reasons behind the no, not being sincere, staff not being aware of tone of voice and body language, not being aware of who is working with them in advance, and not being aware of their schedule.

We are currently tracking individuals who are named as the perpetrator in an incident report but were not found to have been substantiated by APS despite evidence to the contrary. We believe there needs to be a list maintained by the division to prevent direct care providers from jumping from agency to agency.

Behavior Treatment Plans

Behavior Treatment Plans should be in a consistent format like Individual Service Plans created by Support Coordinators. This would allow ease of reading for Support Coordinators, Providers, Direct Care Staff, PRC and HRC. It would ensure that all necessary information be in the plan. It would provide consistency from member to member, agency to agency and district to district. This would prevent agencies from seeking out presenting their plan to the district they feel is easiest to get approval from, as well as help those agencies struggling with creating appropriate plans.

It is hard for our committee to make a determination as to whether an individual is on an appropriate amount of medication or is over medicated. Our committee requests that an expert in this field be provided to review to ensure members are not over medicated.

Our committee requests that it be provided with a behavioral consultant to provide expertise into the effectiveness of the plans that are presented.

Currently DDD has no tracking system to ensure that provider agencies have current BTPs in place for members that are required to have them. There were many plans that were submitted that were way overdue or about to become due again. This is a huge human rights violation as agencies are not properly handling members' behaviors. They hire staff that babysit, rather than follow ISP outcomes and run BTP outcomes. Members' behaviors escalate out of control resulting in provider agencies calling crisis and/or the police and press charges against our members. There is a systemic problem of agencies having a policy of calling the police on our members for behaviors, rather than having appropriately trained staff in place to manage the behaviors. During training, all staff must follow Crisis Prevention Intervention strategies. We are tracking police involvement to track and trend.

Police Involvement

Many times when agencies call "crisis" they are told to call the police. The police do not have the appropriate training to deal with our members. The police, as well as the jails and courts are not the appropriate place for our members. Involving the police can result in tragedy such as death, which was experienced in our district last year.

The jails treat them as a typical criminal and don't understand their unique specialized needs. Members have been denied their medications while in jail resulting in further behavioral and medical issues. The experience with the police, jail and the judicial system causes an escalation of behaviors and/or PTSD. Policy changes need to be instituted to prevent these things from happening. These issues are directly in opposition to laws and policies in place to ensure our members human rights.

Provider Accountability and Provider Report Cards

DDD needs to provide more transparency with members, their families and guardians. When incident reports are made regarding their member, families deserve to know the outcome of the investigation and any course of action taken by DDD or the agency.

Families should be provided a copy of the contract that an agency has with DDD when caring for their member. This provides clarity of what is being expected for their compensation. There should also be transparency as to the amount of compensation received for services rendered.

Families have the right to know who is working with the member, what their background results are, agency policy for drug tests, and violation consequences/follow up when incidents occur.

Many members and their families are afraid to report agencies and direct care staff for the very real fear of retaliation against the member in their care.

Cameras should be allowed in day programs and residential settings if requested by guardian. We have seen all too often DCS and APS come back from their investigations with "unsubstantiated" because it is a he said, she said situation. Cameras would eliminate these ambiguities and provide protection against false allegations for providers. We find that more often than not our members are not believed and are blamed for circumstances that could very easily be abuse. In addition, many times direct care workers are removed from working with vulnerable members for long periods of time while awaiting the results of the investigation.

A report card system needs to be in place so that families can make educated and informed decisions as to the providers that they want to work with. The report card system should utilize feedback from QA, SC and families/guardians and be available on DDD's website for public access. This has become a common practice for professionals like attorneys, doctors, realtors, general contractors etc. and should be no different for providers. Questions such as: How long have they been in business? Number and category of incidents? Were they corrected? Systems in place? How many homes? Total number of clients? Staff ratio? Staff turnover? How often are clients leaving or provider is releasing them? Would be beneficial information.

Agencies experiencing issues should not be given more members to service when they are failing to provide quality of care to the members that they are servicing. There seems to be a lack of accountability of enforcing provider's contracts to the detriment of our members.

Health Issues

In October \$1000 allowance was implemented for dental care for our members over the age of 21. Many members are having teeth pulled resulting in additional health problems, such as digestive issues and gum cancer. Providers are not providing adequate daily dental hygiene to the members.

Diabetes, obesity, digestive and other health issues are often times a direct result of group homes not providing nutritional meals for our members. Direct care staff eat fast food and drink sodas in front of the members which not only provides a poor example but also results in behaviors due to members wanting the fast food and sodas as well.

We read a few incident reports regarding a group home or DTA van arriving at their destination, only to later discover a member was left in the van by themselves. Incidents such as this can lead to neglect, medical issues or death. It is extremely important that group homes and DTAs have systems in place to ensure that this never happens.

Human Rights

Providers are refusing to take and support members in their religious activities because it differs from their own religious beliefs. It is important that agencies train and enforce direct care workers to understand that their job is to support the member in the activities they wish to participate in.

Agencies are not respecting cultural sensitivity of our members. Members are forced to have direct care staff that are very different from the members causing the members to be uncomfortable and not get their needs met. These cultural differences were seen in having a skin color which causes distress, thick accents which caused problems in communication, religious preferences not being respected, meal preparation of an origin not comfortable to member, staff not knowing how to brush hair different from theirs and staff not comfortable with member's pets due to cultural differences. Our members have the right to have staff that they are most comfortable with.

Adequate Residential Settings

There is a lack of agencies able and willing to service members with high behavioral needs. This results in members living for long periods of time in unstable and/or potentially harmful situations where they are not happy. This results in decomposition of the member and a worsening of behaviors. Members have the right to be in a happy stable home.

Behavioral Health Hospitals

There are no behavioral health hospitals in Arizona prepared to appropriately meet the needs of our members when psychiatric hospitalization is required due to medication changes that need to take place in an inpatient setting. They are thrown in with mentally ill, criminals and drug addicts. This is true in outpatient facilities such as UPC and SMI clinics as well. There needs to be specialization for our members that are set apart as their needs are very different due to the developmental issues and would be more effectively managed with specialization. Furthermore, the division between DDD and Regional Behavioral Health causes the dually diagnosed members to navigate an extremely confusing system which has either side pointing fingers at who is supposed to be providing services. Behavioral health needs to be under one umbrella for our members. This collaboration of cooperative care should be a high priority.

ARC Reports

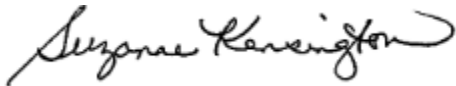
During 2016 The ARC's contract changed from monitoring the quality of life for a sample of the entire DDD residential population to only covering the members from Griswold v. Riley settlement. There are only 57 individuals still living that are covered by the settlement. The ARC is paid \$50,000 per year for this contract. Although we believe that the ARC wasn't providing adequate monitoring and reports, now the rest of members now are not being looked at separately.

Placement	All Other	District East	Statewide
ADH	967	271	1238
Group Home	2497	360	2857
SOGH	29	20	49
Home	25377	8037	33414
ICF	40	11	51
ICR/MR	136	3	139
State Hospital	3	0	3
Desert Vista	7	0	7
ATPC	0	83	83
Totals	29056	8785	37841

BTP Reviewed	IR Reviewed	Meetings Held	Volunteer Hours	Valuation of Donated Hours
299	776	12	892	\$19,972.68

These issues and recommendations have been previously discussed with DDD management via phone, email, District East meetings, statewide meetings, and individual meetings.

This report is a compilation of District East meetings, statewide meetings, review of Behavior Treatment Plans for DE, review of Incident Reports for DE, meetings with families, providers and DDD employees and personal experiences of our committee members during 2016.



Suzanne Kensington, Chairperson