

Highlights of NDAR's Progress in 2010

Mike Huerta
Director, NDAR
Associate Director, NIMH

NDAR

National Database for Autism Research



Achievements

- Increase the **quality and usefulness** of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- Increase the quantity of available data
 - ◆ Federating major ASD data resources (*40,000*)
 - ◆ Receiving data from 60 NIH projects (*45,000*)
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Achievements

- Increase the **quality and usefulness** of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- Increase the quantity of available data
 - ◆ Federating major ASD data resources (40,000)
 - ◆ Receiving data from 60 NIH projects (45,000)
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Achievements

- Increase the quality and usefulness of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- **Increase the quantity of available data**
 - ◆ Federating major ASD data resources (40,000)
 - ◆ Receiving data from 60 NIH projects (45,000)
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Achievements

- Increase the quality and usefulness of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- Increase the **quantity** of available data
 - ◆ **Federating major ASD data resources (40,000)**
 - ◆ Receiving data from 60 NIH projects (45,000)
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Federation with Major ASD Data Resources

■ Federated in 2010

- ◆ AGRE (Autism Speaks)
- ◆ IAN (Kennedy Krieger)
- ◆ ATP (Autism Speaks)
- ◆ Pediatric MRI Data Repository

■ Planned for Federation in 2011 – 2012

- ◆ Yale resources
- ◆ SFARI (Simons Foundation)
- ◆ NIMH Genetics Repository
- ◆ NIH Database for Genotype & Phenotype (dbGaP)
- ◆ Other agencies, etc.

Achievements

- Increase the quality and usefulness of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- Increase the **quantity** of available data
 - ◆ **Federating major ASD data resources (40,000)**
 - ◆ Receiving data from 60 NIH projects (45,000)
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Achievements

- Increase the quality and usefulness of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- **Increase the quantity of available data**
 - ◆ Federating major ASD data resources (40,000)
 - ◆ **Receiving data from 60 NIH projects (45,000)**
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

Achievements

- Increase the quality and usefulness of data
 - ◆ Promulgating GUID use – common identifier
 - ◆ Enhancing data dictionary – common language
 - ◆ Autism Informatics Consortium – common grid
- Increase the **quantity** of available data
 - ◆ Federating major ASD data resources (40,000)
 - ◆ **Receiving data from 60 NIH projects (45,000)**
 - ◆ Autism Centers of Excellence
 - ◆ ARRA Grants
 - ◆ Other grants and contracts

NDAR now sharing ASD research data

Sharing ASD Data in NDAR

Sharing ASD Data in NDAR

Shared October 2010

	ACEs	CPEA/STAART	Pediatric MRI	ARRA	Total
Collections	8	3	-	-	11
Total Unique Subjects	873	9258	-	-	10131
Clinical Data Structures Used	30	73	-	-	103
Subjects with Clinical Measure Data	873	9258	-	-	10131
Genomic Data Structures	11	0	-	-	11
Subjects with Genomic Data	11	0	-	-	11
Subjects with Brain Images	10	0	-	-	10

Sharing ASD Data in NDAR

To Be Shared November 2010

	ACEs	CPEA/STAART	Pediatric MRI	ARRA	Total
Collections	9	3	1	23	36
Total Unique Subjects	934	9258	555	1523	12270
Clinical Data Structures Used	30	73	57	66	226
Subjects with Clinical Measure Data	924	9258	555	1501	12248
Genomic Data Structures	11	0	0	17	28
Subjects with Genomic Data	11	0	0	19	29
Subjects with Brain Images	10	0	554	50	614

Sharing ASD Data in NDAR

To Be Shared April 2011

	ACEs	CPEA/STAART	Pediatric MRI	ARRA	Total
Collections	15	3	1	23	42
Total Unique Subjects	2723	9258	555	1523	14059
Clinical Data Structures Used	30	73	57	66	226
Subjects with Clinical Measure Data	2723	9258	555	1501	14037
Genomic Data Structures	11	0	0	17	28
Subjects with Genomic Data	11	0	0	19	29
Subjects with Brain Images	10	0	554	50	614

NDAR – Looking Forward

NDAR is poised to meet the IACC SP Objective:

Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the National Database for Autism Research (NDAR) and link NDAR with other existing data resources by 2012.