

**KENTUCKY COMMISSION ON SERVICES AND SUPPORTS FOR
INDIVIDUALS WITH INTELLECTUAL
AND OTHER DEVELOPMENTAL DISABILITIES
A G E N D A
MEETING ROOM 131 CAPITOL ANNEX
March 3, 2016
1:30 – 3:30 p.m.**

OPENING REMARKS	Judge Tim Feeley, Deputy Secretary Wendy Morris, Acting Commissioner
REVIEW of MINUTES	Judge Tim Feeley, Deputy Secretary Wendy Morris, Acting Commissioner
REVISE HB 144 GOALS AND RESTRUCTURE COMMITTEES	Missy McKiernan
DMS UPDATES	Leslie Hoffmann, DMS
COMMITTEE REPORTS	<ul style="list-style-type: none"> • Community Integration—MaryLee Underwood & Jim Chesser • Health & Wellness—Dr. Kathy Sheppard-Jones • Participant Directed Services--Patty Dempsey & Cathy Edwards
COMMUNITY-BASED SUPPORTS FOR MEDICALLY-FRAGILE INDIVIDUALS	<ul style="list-style-type: none"> • MaryLee Underwood • Diana Oliver
AGING AND DOWN SYNDROME RESEARCH STUDY – University of Kentucky, Sanders-Brown Center on Aging	<ul style="list-style-type: none"> • Roberta Davis, Research Administrative Coordinator • Dr. Frederick Schmitt, Project Investigator
COMMONWEALTH COUNCIL ON DEVELOPMENTAL DISABILITIES STRATEGIC PLAN	MaryLee Underwood, Executive Director
PUBLIC COMMENTS	
UPCOMING MEETING DATES	June 2, 2016 September 8, 2016 December 8, 2016

**KENTUCKY COMMISSION
ON
SERVICES AND SUPPORTS
FOR INDIVIDUALS WITH INTELLECTUAL
AND OTHER DEVELOPMENTAL DISABILITIES**

**December 3, 2015
Legislative Research Commission
131 Capitol Annex
Frankfort, Kentucky**

MEMBERS PRESENT:

Commissioner Mary Begley	Julie Sweets
Tabitha Burkhart-Wilson	Cathy Edwards
Leslie Hoffmann for Commissioner Lisa Lee	James C. Chesser
Dr. Kathy Sheppard-Jones	Andrew A. Venetianer
MaryLee Underwood	Brenda Hosford
D. Brandon Griffith	Gayle J. DiCeasare
Missy R. McKiernan	Lynn M. Braker
	Patty Dempsey

MEMBERS ABSENT:

Deputy Secretary Eric Friedlander	Senator Julie R. Adams
Buddy Hoskinson	Christopher D. George
Representative Joni Jenkins	Donald Putnam
Representative David Watkins	Peter A. Perry
Senator Tom Buford	Melissa David

WELCOME

Commissioner Begley opened the meeting and welcomed Commission Members as well as members of the audience.

Commissioner Begley commended the work and advocacy of Deputy Secretary Eric Friedlander.

In recognition of events that occurred in San Bernardino, California, Commissioner Begley conducted a moment of silence prior to conducting the meeting.

REVIEW OF THE MINUTES:

Minutes from the September 3, 2015 meeting were reviewed. A request from Missy McKiernan to amend the minutes to reflect there are currently three (3) outpatient clinics located in the state: Oakwood Specialty Clinic located on the grounds of Oakwood ICF/IID, Lee Specialty Clinic located near Bingham Gardens ICF/IID, and Hazelwood Clinic located on the grounds of Hazelwood ICF/IID.

Minutes were approved with the requested change.

COMMITTEE REPORTS:

Community Integration

MaryLee Underwood and Jim Chesser

- Committee met on November 19th and elected MaryLee Underwood and Jim Chesser to serve as co-chairs of the Committee
- The University of Kentucky's Martin School of Public Policy and Administration prepared "**A Report on Supports for Community Living Waiver Program: Paying the Costs of Background Checks and Other Requirements for Direct Service Workers**" for the Commonwealth Council on Development Disabilities on June 9, 2014. A copy of the report was included in each member's packet for their review. The Community Integration and the Participant Directed Services (PDS) Committees continue to collaborate on this particular issue.
- Committee, after reviewing the National Core Indicator Data and the Quality Improvement Committee Recommendations, identified the following issues as the priority items the Committee will focus upon during 2016:
 - Flexibility of services throughout all waivers and including the Hart Supported Living program;
 - Overall funding of services for individuals with intellectual/developmental disabilities;
 - Employment costs for individuals who choose to participant-direct any or all of their supports and continue the collaboration with the PDS Committee;
 - Explore strategies to continue the decrease of loneliness as reported in the NCI data including training for providers; and
 - Increase in flexibility of addressing transportation needs, including addressing needs of individuals who reside in rural communities where transportation may impose barriers for individuals' participation in community and recreational events/activities.
- Committee Co-Chair MaryLee Underwood also contacted the Health-Wellness Committee Chair, Dr. Kathy Sheppard-Jones, to refer two (2) identified issues for their consideration:
 - Increased use of psychotropic medications in the Supports for Community Living Medicaid waiver program as identified in NCI data; and
 - Increased risk for development of Alzheimer's disease associated with Down Syndrome.
- The Community Integration Committee is currently scheduled to meet again on February 19, 2016 from 1-3 p.m. at the Human Development Institute's Coldstream Office.

Health-Wellness

Dr. Kathy Sheppard-Jones

- Health-Wellness Committee met on November 20th and Dr. Kathy Sheppard-Jones will serve as Committee Chair
- The Human Development Institute (HDI) Health Program Coordinator continues to collaborate with the University of Illinois-Chicago on health initiatives for individuals with intellectual/developmental disabilities related to diet and exercise

- The Committee is aware that individuals with disabilities in Kentucky generally have increased rates of smoking, increased blood pressure and obesity, and a decreased rate of physical exercise. The Committee will continue efforts in identifying ways to promote appropriate diet and exercise across all waiver programs and include direct support professionals in these initiatives.
- Dr. Sheppard-Jones acknowledged the referral of issues related to increased risk of Alzheimer's disease associated with Down Syndrome and the increased usage of psychotropic medications in the SCL program and will address these concerns with the remainder of the Health-Wellness Committee members.
- Next meeting date has not been set, but if anyone is interested in participating on the Committee, please contact Barb Locker at DDID for information.

Participant Directed Services

Patty Dempsey and Cathy Edwards

- The Participant Directed Services (PDS) Committee met on October 20th.
- Patty Dempsey and Cathy Edwards will continue to serve as co-chairs of the Committee
- Acknowledged three new Commission members who joined the PDS Committee: Julie Sweets, Brandon Griffith, and Gayle DiCesare.
- The Committee identified the following goals/objectives for 2016:
 1. Goal 1: PDS participants will increase self-advocacy by self-directing their person-centered plan (PCP).
 2. Goal 2: PDS families will increase their advocacy on behalf of participants by directing the participant's PCP.
 3. Goal 3: Participants and families should receive adequate training related to PDS programs across all waivers.
 - 3.1 Advocate for each appropriate CHFS agency to include participants and/or their families to participate in trainings provided to provider agencies related to participant-directed services.
 - 3.2 Ensure participants and/or their families without internet access receive the same information in an alternative format.
 4. Goal 4: Establish an advocacy coalition, including but not limited to the ARC of Kentucky, Autism Society of the Bluegrass, KY Self-Advocates for Freedom (KYSAFF), officials from CHFS/Department for Behavioral Health, Developmental and Intellectual Disabilities
- The need for transportation for community involvement was reiterated. Transportation should not just be limited to medical appointments or to only daytime hours but should include evening hours so individuals can access community events and/or recreational activities, such as going out to eat with friends after work, going to movies, etc.
- The Committee presented the following recommendations to the Commission:
 1. Include participants and/or their families in the construction of new waivers and regulations. The Committee encourages the appropriate CHFS agency to include participants and/or families in discussions that pertain to new waivers or waiver changes being considered, particularly when pertaining to self-directed services.
 2. Notify participants whenever regulation changes are proposed that will impact their services and supports. (Currently participants do not receive regulation change information until after the proposed change(s) have taken place).

3. Allow participants to change line items as need within their Plan of Care (budgets) across all waivers. Medicaid waivers through the Center on Medicaid Services are intended to give people with disabilities more opportunities to better community living and control of their lives. However, prohibiting changes in line items in the individual Plan of Care (budget) creates barriers to the flexibility intended in self-directing services. Also, when preparing a Plan of Care, it would be helpful if the participant could be provided a copy of the regulations by the Case manager as they may not have online service.
- Discussion was held regarding how other states are using YouTube videos to explain regulations that people with intellectual/developmental disabilities can understand.
 - The use of KARES by individuals who choose to participant direct their supports was questioned. For questions or assistance related to KARES an individual may contact: KARES.helpdesk@ky.gov The PDS Committee will gather information related to KARES and review the impact upon individuals who participant direct supports.
 - The Committee's recommendations were accepted by the Commission and will be forwarded to the appropriate CHFS personnel for responses.
 - The Committee has not set a date for the next meeting.

REVISE HB 144 GOALS AND RESTRUCTURE COMMITTEES Missy McKiernan

- Commission Member Missy McKiernan requested that all Commission Members review the 2012 Commission Goals contained in the meeting packet to determine if they are still appropriate or if they should be revised.
- A brief discussion was held. Jim Chesser reminded the Commission that the 2012 goals were designed as 5-year goals and the Commission is in the third year of implementation. It was determined that each Committee will review the goals in upcoming committee meetings and any recommendations for changes will be forwarded to Barb Locker for placement on the March meeting agenda
- A reminder was also announced that committees are open to members from the community who would like to volunteer their time and efforts on committee initiatives.

HB 144 MEMBERSHIP STATUS Commissioner Mary Begley

- Commissioner Begley reviewed the list of current Commission Members whose terms will expire in July 2016
- The list of members was located in the Member's meeting packet and those members who are eligible for reappointment have been contacted by DDID and provided the application necessary for request of reappointment.
- A printed copy of the announcement and the applicable application were provided in the meeting materials and notices were distributed electronically by the Department utilizing various partners' listservs.
- Applications are being accepted until February 15, 2016.
- Commission Members were reminded that all applications are submitted to the Governor's Office and appointments to the Commission are made by the Governor's Office.

DMS UPDATES

Leslie Hoffmann

- Review of Michelle P. Waiver recommendations from the Community Integration Committee was provided. Several issues were addressed in an oral presentation at the September 3rd meeting. Members received written responses to the recommendations which were contained in the meeting packet and included attachments referenced in the September 3rd oral responses.
- Review of the Participant-Directed Services and Community Integration Committee Recommendations was provided and written responses were contained in the Member packets. MaryLee Underwood asked to clarify that of the recommendations, only one (1) could have traction but is beyond the scope of the HB144 Commission and requires legislation. This was affirmed by Ms. Hoffmann
- Review of the Supports for Community Living Emergency Waiting List. The Department for Medicaid Services continues to work with the Centers for Medicare and Medicaid Services (CMS) to release additional slots
- Information related to allocation of slots across all Home and Community Based Waiver programs was reviewed.
- A provider webinar was held in November related to waiver changes in the services of Occupational/Physical/Speech Therapies. These therapies are available to waiver participants through traditional Medicaid services. Individuals in HCB waiver programs will continue to receive the therapies as long as medical necessity requirements have been met.
- MaryLee Underwood asked where ABA Therapy for children with a diagnosis of Autism falls within the HCB Waiver. Lynn Flynne, representative from the Department of Medicaid Services clarified these services are available through the Medicaid State Plan using the individual's Medicaid card. For questions related to ABA Therapeutic Services within the State Plan, individuals may contact Kristina Hayden at the Department for Medicaid Services.

HCB STATEWIDE TRANSITION PLAN UPDATES Leslie Hoffmann and Lynne Flynn

- Presentation provided by Leslie Hoffmann and Lynne Flynn related to the CMS Final Rule HCB Statewide Transition Plan
- Andrew Venetianer asked for clarification of the term "heightened scrutiny"
- Missy McKiernan requested clarification regarding the number of providers across waivers who meet the definition of "heightened scrutiny"
- All comments regarding the HCB Statewide Transition Plan from the first public forums, any changes or amendments to the state plan as a result of comments, and comments from second round public forums will be submitted to CMS in one document.

TESTIMONY FROM PARENT

Kristy Slusser

- Request from Camille Collins of Protection and Advocacy made in advance for parent to address the Commission
- Kristy Slusser provided information regarding her son who is currently in an out-of-home placement and not able to obtain an emergency SCL Slot due to the Emergency Waiting List and the lack of slots available. The parent was advised to remain after the

conclusion of the meeting and public forum to talk with Tabitha Burkhart-Wilson, Psychological Program Administrator from the Department of Behavioral Health, Developmental and Intellectual Disabilities regarding the situation.

ADDITIONAL COMMENTS

- Jim Chesser experienced difficulty gaining access through a security entrance for the meeting site that he has traditionally utilized. Future meeting locations will be checked for easy accessibility and security protocols addressed in advance of the meeting.
- Lynn Braker announced that she is a chairperson for a group at the University of Kentucky's Sanders Brown Center for Aging that is working on a 10-year study related to Alzheimer's disease. She will be serving on the Health-Wellness Committee of HB 144.
- Andrew Venetianer reminded Commission Members of the 874K to be held in February 2016. A flyer was included in each member's meeting packet of materials.

MEETING ADJOURNED

Commissioner Mary Begley

- Commission members were reminded that meeting dates for 2016 are located on the bottom of the agenda. Locations are yet to be determined.
- Requested and received motion and second to adjourn the HB 144 Commission Meeting and move directly into the Department for Medicaid Services HCB Statewide Transition Plan Public Comment Period.

SCL Waiting List Report

As of 2/29/2016

Future Planning	Urgent	Emergency	Total
2,008	38	39	2,085

Of those on the waiting list, 96.1% (2,003) report receiving services.

Funding Source or Services Reported by those on the waiting list:

Funding Source or Service Reported	#	%
Case Management	1,390	66.7%
Michelle P Waiver	1,186	56.9%
Respite	894	42.9%
Day Program	733	35.2%
School	680	32.6%
Speech Therapy	677	32.5%
Mental Health	576	27.6%
Transportation	535	25.7%
Occupational Therapy	529	25.4%
Behavior Support	528	25.3%
other	421	20.2%
Physical Therapy	347	16.6%
Supported Employment	288	13.8%
HCB Waiver	262	12.6%
EPSDT	226	10.8%
Residential	187	9.0%
In home support	176	8.4%
Home Health	135	6.5%
Supported Living	122	5.9%
ABI -Acute(Acquired Brain Injury-Waiver)	11	0.5%
ABI -LTC(Acquired Brain Injury Long Term Care-Waiver)	2	0.1%

Supports for Community Living Allocations
 FY16 Progress & Totals FY08-FY15

FY16 Progress			
Date	ER	URGENT	Total
Jul-15	51	1	52
Aug-15	58	1	59
Sept 15	49	1	50
Oct 15	58	0	58
Nov 15	34	1	35
Dec 16	25	0	25
Jan 16	20	0	20
Feb 16	2	0	2
YTD	250	4	254

Region														
1	2	3	4	5	6	7	8	10	11	12	13	14	15	
3	1	3	3	7	5	3	1	1	2	4	3	3	13	
1	4	2	1	4	11	1	0	3	1	5	3	7	16	
1	2	5	3	9	7	5	0	3	0	2	3	4	6	
2	3	0	4	9	10	4	0	6	1	3	2	5	9	
2	1	4	4	5	6	1	0	1	0	1	1	1	8	
1	3	1	3	1	5	2	0	0	2	1	2	1	3	
1	0	0	1	3	4	1	0	0	0	1	1	1	7	
0	0	0	0	1	0	0	0	0	0	0	1	0	0	
9	11	14	15	34	39	14	1	14	4	15	12	20	52	

FY08 - FY15						
Fiscal Year	ER	PASRR	DCBS	MFP	Urgent	Total
FY15	495	14	4	32	8	553
FY14	342	NA	NA	24	14	380
FY13	397	NA	NA	38	216	651
FY12	226	2	30	81		339
FY11	133	5	33	0		171
FY10	136	9	30	0		175
FY 09	159	15	22	0		196
FY08	197	33	33	0		263

Region														
1	2	3	4	5	6	7	8	10	11	12	13	14	15	
29	27	28	58	31	143	17	2	14	18	21	15	47	103	
7	26	13	33	20	92	32	7	10	12	24	19	18	67	
17	42	36	54	39	172	65	3	21	13	20	21	33	115	
14	17	11	26	10	62	32	0	11	14	30	16	37	59	
7	8	6	11	16	39	8	1	6	4	12	12	16	25	
10	14	4	5	16	31	11	0	8	8	16	15	16	21	
4	6	8	22	13	41	15	1	14	12	7	7	21	25	
3	17	9	20	24	62	17	5	12	10	18	16	11	39	



KENTUCKY

Cabinet for Health and Family Services

DEPARTMENT FOR MEDICAID SERVICES

HOME AND COMMUNITY BASED SERVICES WAIVERS UPDATE

HB144 COMMISSION

PRESENTED BY:

LESLIE HOFFMANN, DIRECTOR, DIVISION OF COMMUNITY ALTERNATIVES, DEPARTMENT FOR MEDICAID SERVICES

LYNNE FLYNN, POLICY ADVISOR, COMMISSIONER'S OFFICE, DEPARTMENT FOR MEDICAID SERVICES

MARCH 3, 2016

Update on Ancillary Services

PT/OT/ST Waiver Transition to State Plan

Since DMS cannot cover PT/OT/ST in both the waivers and the state plan, DMS is transitioning these services from the HCBS waivers into the state plan at the time of renewal for each of the HCBS waivers.

Transition in Progress

HCB

- Submitted renewal application to CMS without PT/OT/ST in April
- Filed HCB regulations without PT/OT/ST as covered services in September
- Transition anticipated: **April, 2016**

SCL

- Submitted renewal application to CMS without PT/OT/ST in June
- Filed SCL regulations without PT/OT/ST as covered services in August
- Transition anticipated: **May, 2016**

Upcoming Transition

ABI-LTC

- Submit renewal application to CMS on April 1, 2016 (effective date of July 1, 2016)
- File ABI-LTC regulations without PT/OT/ST as covered services in April
- Transition anticipated: **September, 2016**

MPW

- Submit renewal application to CMS on June 1, 2016 (effective date of September 1, 2016)
- File MPW regulations without PT/OT/ST as covered services in May
- Transition anticipated: **November, 2016**

ABI

- Submit renewal application to CMS on October 1, 2016 (effective date of January 1, 2017)
- File ABI regulations without PT/OT/ST as covered services in August
- Transition anticipated: **February, 2017**

Update on HCBS Federal Final Rules

Kentucky Implementation

Following is a summary of major implementation activities carried out by CHFS staff, with input and involvement from stakeholders.

Completed Activities	
January – March 2015	<ul style="list-style-type: none"> • Presented rules to participants and obtained their input on implementation at Participant forums throughout the state • Developed compliance plan template tool and hosted provider webinar for input
April – June 2015	<ul style="list-style-type: none"> • Distributed compliance plan templates to providers and designed evaluation criteria • Received public comments for HCB and SCL waiver renewals • Submitted HCB and SCL waiver renewals
July – September 2015	<ul style="list-style-type: none"> • Evaluated providers’ compliance plan templates • Filed revised waiver regulations • Presented rules to various provider and advocacy groups
October – December 2015	<ul style="list-style-type: none"> • Updated provider compliance categories and summarized provider counts • Distributed compliance plan template evaluations to providers • Drafted and submitted updated statewide transition plan to CMS
Upcoming Activities	
January – March 2016	<ul style="list-style-type: none"> • Design the process for category 4 on-site reviews • Conduct on-site reviews and collect evidence to submit to CMS • Provide updates to providers, self-advocates, family members, and advocates

Inclusion of HCBS Rules in DMS Regulations

The following table is a summary of the pieces of the HCBS Final Rules that were incorporated in revised DMS regulations, as well as the actual or proposed effective date of those regulations.

	HCBS Final Rules	Effective Date
ABI	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements • Conflict-free case management • First round setting requirements 	February 5, 2016
ABI-LTC	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements • Conflict-free case management • First round setting requirements 	February 5, 2016
MIIW	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements 	February 5, 2016
HCB	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements • Conflict-free case management • First round setting requirements 	April, 2016
MPW	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements • Conflict-free case management • First round setting requirements 	May, 2016
SCL	<ul style="list-style-type: none"> • Person-centered planning • Service plan requirements • Conflict-free case management • First round setting requirements 	May, 2016

HCBS Waiver Applications – Renewal Dates

The following table is a summary of the timelines associates with each of the HCBS waiver renewals.

	Public Comment	Due Date to CMS	Effective Date
HCB	4/10/2015 – 5/10/2015	4/1/2015	April, 2016* *pending approval from CMS
SCL	4/29/2015 – 5/29/2015	6/1/2015	May, 2016* *pending approval from CMS
MIIW	5/30/2015 – 6/29/2015	7/1/2015	1/8/2016
ABI-LTC	2/26/2016 – 3/26/2016	4/1/2016	7/1/2016
MPW	4/25/2016 – 5/25/2016	6/1/2016	9/1/2016
ABI	8/29/2016 – 9/28/2016	10/1/2016	1/1/2017

Waiver Slots

Waiver slots are unduplicated which means if a participant even uses one service in a waiver year, the slot cannot be reused or refilled until the following waiver year. Below is a summary of waiver slots and current wait lists.

	Waiver Slots	Wait List	Notes
ABI	383	0	
ABI-LTC	320	187	The 320 slot total includes slots reserved for MFP.
HCB	17,050	0	
MPW	10,500	4,769	
SCL	4,701	2,016	240 additional slots are approved to be added.

Slots Included in Biennium Budget

The following appropriations were included in the upcoming budget, but these figures do not guarantee inclusion in the enacted budget.

SCL

The Executive Budget includes General Fund of \$814,400 in fiscal year 2016-2017 and \$2,603,000 in fiscal year 2017-2018 to continue the roll-out of the Supports for Community Living program. There will be **41 slots added in fiscal year 2016-2017** and an additional **130 slots added in fiscal year 2017-2018** for a **total of 171** slots added over the biennium.

MPW

The Executive Budget includes General Fund of \$946,100 in fiscal year 2016-2017 and \$1,989,000 in fiscal year 2017-2018 to continue the roll-out of the Michelle P. program. There will be **83 slots added in fiscal year 2016-2017** and an additional **166 slots added in fiscal year 2017-2018** for a **total of 249** slots added over the biennium.

Stakeholder Engagement

The Cabinet for Health and Family Services (CHFS) understands the importance of including self-advocates, advocates, family members, and providers in the HCBS Federal Final Rules implementation. All stakeholders groups are affected by these rules and we want all to have a seat at the table as we work to implement them.

- **Statewide Advisory Committees**
 - Advisory Council for Medical Assistance (MAC)
 - Technical Advisory Committees (TACs)
- **Public Forums**
- **Work Groups**
- **Public Comment Periods**
 - Statewide Transition Plan
 - Waiver Applications
 - Regulations

HCBS Final Rules – Stakeholder Input

CHFS recently hosted two meetings for self-advocates, advocates, families, and providers to obtain their input on how providers can demonstrate their compliance with the HCBS Final Rules.

For stakeholder convenience, there were two in-person meetings on different days and times, and each meeting also had a webinar option to minimize the need to travel. The attendees provided valuable suggestions and recommendations into the HCBS Final Rules implementation. Below is a summary table of attendance at the meetings.

Meeting	Attendance		
	In-Person	Webinar	Total
Wednesday, February 10, 2016 1:30 – 3:30 PM	21	217	238
Thursday, February 11, 2016 10:00 AM – 12:00 PM	23	174	197

CHFS is using this stakeholder input as it finalizes the on-site review tools that will be used to collect information on the category 4 providers.

Opportunities for Public Input

Participants, families, and other advocates have had, and will continue to have, several opportunities to provide input into the Kentucky waiver programs.

Previous Opportunities

- **May, 2015:** SCL waiver renewal public comment period
- **November, 2015:** Updated statewide transition plan public comment period
- **November, 2015:** HCB waiver regulation public comment period
- **February, 2016:** HCBS Final Rules Stakeholder Input Meetings

Upcoming Opportunities

- **March, 2016:** ABI-LTC waiver renewal public comment period
- **May, 2016:** MPW renewal public comment period
- **August, 2016:** Updated statewide transition plan public comment period (opportunity for public to comment on the compliance of specific providers)

**The ABI-LTC waiver renewal is currently posted for public comment:
<http://chfs.ky.gov/dms/>**

Residential Settings

The following summary table includes counts and percentages of residential settings in each compliance category.

Compliance Level	Residential Settings	
	Settings	%
Category 1: Fully align with the federal requirements	0	0%
Category 2: Do not comply with the federal requirements and will require modifications	1,436	85%
Category 4: Are presumptively non-HCB but for which the state will provide evidence to show that those settings do not have the characteristics of an institution and do have the qualities of HCB settings (to be evaluated by CMS through the heightened scrutiny process)	252	15%

Non-Residential Settings

The following summary table includes counts and percentages of non-residential settings in each compliance category.

Compliance Level	Non-Residential Settings	
	Settings	%
Category 1: Fully align with the federal requirements	19	6%
Category 2: Do not comply with the federal requirements and will require modifications	277	90%
Category 4: Are presumptively non-HCB but for which the state will provide evidence to show that those settings do not have the characteristics of an institution and do have the qualities of HCB settings (to be evaluated by CMS through the heightened scrutiny process)	12	4%

Next Steps

The following table summarizes the next steps for providers in each of the compliance categories.

Compliance Category	Immediate Next Steps	Ongoing Compliance
Category 1	No action required.	
Category 2	Review compliance plan evaluation and make modifications to become compliant in areas of non-compliance.	CHFS will evaluate ongoing compliance with the HCBS Federal Final Rules at the time of re-certification for each provider.
Category 3	N/A – no provider in Kentucky was scored as category 3.	
Category 4	CHFS will be scheduling an on-site review with each setting in this category to validate that the setting meets the description of “presumed not to be home and community-based”.	<p>If the setting remains as a category 4, it will be published for public comment in the next iteration of the Statewide Transition Plan.</p> <p>CHFS will submit all evidence, including public input, that the setting is home and community-based to CMS; CMS will conduct heightened scrutiny.</p>

**HB 144 – Participant Directed Services Committee
Recommendations
March 3, 2016**

The Participant Directed Services/Consumer Directed Option Committee makes the following recommendations to the HB 144 Commission. These recommendations are in line with the goals and objectives of the Committee to promote community education, outreach and access to services and supports that meets the needs and expectations of participants

1. Recipients of the Michelle P. Waiver that choose to self-direct their services are concerned about the lack of flexibility in their Plans of Care and the 40 hour per week limit that is to become effective on April 1, 2016. Some recipients are currently receiving more than 40 hours but there is no increase to their budgets. The PDS/CDO Committee encourages the Department for Medicaid Services to make a change in the Michelle P. Waiver Regulation language to allow for more than 40 hours as necessary per Plan of Care.
2. The spending reductions in the Governor's proposed budget were brought to the attention of the PDS/CDO Committee. While we understand the challenges facing our state, the Committee is deeply concerned that the spending reductions of 4.5% would mean \$8.2 million of services that would be impacted in this fiscal year and some \$16.5 million in the next fiscal year in the Department for Behavioral Health, Developmental and Intellectual Disabilities. The PDS/CDO Committee opposes these cuts. The PDS/CDO Committee recommends that no reductions occur to the dollars already in place.
3. The Committee also discussed the number of placements in the Governor's proposed budget for the Supports for Community Living and the Michelle P. Waiver. The Waiting List for the SCL Waiver is 2,002 and for the Michelle P. Waiver is 4,900. The proposed budget reflects 41 SCL new waiver placements in fiscal 2016-17 and an additional 130 in fiscal 2017-18. The proposed budget reflects 83 Michelle P. Waiver slots in 2016-17 and an additional 166 in 2017-18. Due to the number on the waiting lists already and some 12,400 aging caregivers caring for their family members, while not a formal recommendation, we ask these number be increased.

(Note - On September 3, 2015, the PDS Committee had recommended funding for SCL and MPW to be included in the Cabinet for Health and Family Services fiscal budget 2017-2018 at a 20% increase each year that would significantly impact the SCL and MP Waiting Lists. The Dept. for Medicaid staff indicated at the December meeting they were including 200 each year in the CHFS budget but that # is not reflected in the proposed budget on the table).

Alzheimer's Disease in People with Down Syndrome

FACT SHEET

Alzheimer's and Down Syndrome — Get the Facts

- The Connection between Down Syndrome and Alzheimer's Disease
- Alzheimer's Disease Symptoms
- Down Syndrome and Alzheimer's Research
- Participating in Research
- For More Information

People with Down syndrome are living longer than ever before. Getting older can bring new health challenges, including Alzheimer's disease.

The Connection between Down Syndrome and Alzheimer's Disease

Many, but not all, people with Down syndrome develop Alzheimer's disease when they get older. Alzheimer's is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks.

Alzheimer's disease is the most common cause of dementia among older adults. Dementia is the loss of cognitive functioning—thinking, remembering,

and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.

People with Down syndrome are born with an extra copy of chromosome 21, which carries the APP gene. This gene produces a specific protein called amyloid precursor protein (APP). Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. By age 40, almost all people with Down syndrome have these plaques, along with other protein deposits, called tau tangles, which cause problems with how brain cells function and increase the risk of developing Alzheimer's dementia.

However, not all people with these brain plaques will develop the symptoms of Alzheimer's. Estimates suggest that 50 percent or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age, many now into their 70s.

Alzheimer's Disease Symptoms

Many people with Down syndrome begin to show symptoms of Alzheimer's disease in their 50s or 60s. But, like in all people with Alzheimer's, changes in the brain that lead to these symptoms are thought to begin at least 10 years earlier. These brain changes include the buildup of

plaques and tangles, the loss of connections between nerve cells, the death of nerve cells, and the shrinking of brain tissue (called atrophy).

The risk for Alzheimer's disease increases with age, so it's important to watch for certain changes in behavior, such as:

- increased confusion
- short-term memory problems (for example, asking the same questions over and over)
- reduction in or loss of ability to do everyday activities

Other possible symptoms of Alzheimer's dementia are:

- seizures that begin in adulthood
- problems with coordination and walking
- reduced ability to pay attention
- behavior and personality changes, such as wandering and being less social
- decreased fine motor control
- difficulty finding one's way around familiar areas

If you notice any of these changes, see a healthcare provider to find out more. Keep in mind, though, that not all dementia symptoms are caused by Alzheimer's disease. Other conditions, such as medication side effects, depression, and kidney, thyroid, and liver problems, can also cause dementia symptoms. Some of these conditions can be treated and reversed.

Currently, Alzheimer's disease has no cure, and no medications have been approved to treat Alzheimer's in people with Down syndrome.

Down Syndrome and Alzheimer's Research

Alzheimer's can last several years, and symptoms usually get worse over time. Scientists are working hard to understand why some people with Down syndrome develop dementia while others do not. They want to know how Alzheimer's disease begins and progresses, so they can develop drugs or other treatments that can stop, delay, or even prevent the disease process.

Research in this area includes:

- basic studies to improve our understanding of the genetic and biological causes of brain abnormalities that lead to Alzheimer's
- observational research to measure cognitive changes in people over time
- studies of biomarkers (biological signs of disease), brain scans, and other tests that may help diagnose Alzheimer's—even before symptoms appear—and show brain changes as people with Down syndrome age
- clinical trials to test treatments for dementia in adults with Down syndrome. Clinical trials are the best way to find out if a treatment is safe and effective in people.

Participating in Research

New treatments, tests, and other discoveries would not be possible without volunteers who participate in clinical studies and trials. By volunteering, people can help others, receive care from medical providers, and possibly test new treatments.

Volunteers and their caregivers should consider a study's risks as well as its benefits. For example, a new drug being

tested may have potential side effects. Researchers must follow federal and international rules to ensure that all participants are safe and that their personal information remains confidential. Study staff can explain safety and other issues and answer questions as you decide whether to participate in a research study or clinical trial.

But not everyone can participate in a clinical trial. Studies have specific requirements that people must meet to participate. For example, participants must be of a certain age, have a certain diagnosis, or have a specific genetic makeup. These requirements help ensure that the results of a study are reliable and useful.

Family members and other caregivers play an important role for adults with Down

syndrome who participate in clinical research. They may be asked to provide consent or permission for the person with Down syndrome to take part in the study, accompany the person to study visits, and answer health questions about him or her.

“Informed consent” is a process in which researchers explain the study in detail, describe all the possible risks and benefits of the study, and clarify participants’ rights. Those who decide to participate sign a written agreement stating that they understand the risks and benefits and agree to participate in the study. If a person cannot provide this consent, a legally authorized representative, such as a family member or caregiver, may give permission. The person with Down syndrome would also need to agree, called assent, to be in the study.

There are many ways to learn about research opportunities

- Join **DS-Connect**[®], a voluntary, confidential, online registry from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (part of the National Institutes of Health, or NIH). You, your legally authorized representative, or your guardian can submit information about your health and choose to be contacted about research opportunities, if desired. Visit <https://dsconnect.nih.gov> or email DSCConnect@nih.gov for more information and to sign up.
- Search the National Institute on Aging’s Alzheimer’s disease clinical trials finder, www.nia.nih.gov/alzheimers/clinical-trials.
- Look at the National Down Syndrome Society’s directory of studies, www.ndss.org/resources/research/directory-of-current-studies.
- Visit NIH’s “Clinical Research Trials and You,” www.nih.gov/health/clinicaltrials.

For More Information

Alzheimer's Disease Education and Referral (ADEAR) Center

1-800-438-4380 (toll-free)

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education, training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and other dementias, find clinical trials, and sign up for email updates.

Down Syndrome and Alzheimer's Disease

An Introduction to Alzheimer's Disease

www.ndss.org/resources/aging-matters/alzheimers-disease/an-introduction-to-alzheimers-disease

A Caregiver's Guide to Down Syndrome & Alzheimer's Disease

www.ndss.org/resources/aging-matters/alzheimers-disease/a-caregivers-guide-to-down-syndrome-and-alzheimers-disease

Down Syndrome and Alzheimer's Disease

www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp

Aging and Down Syndrome: A Health & Well-Being Guidebook

www.ndss.org/global/aging-and-down-syndrome.pdf

Down Syndrome Research and Resources

Down Syndrome Consortium

<http://downsyndrome.nih.gov>

Down Syndrome: Overview

www.nichd.nih.gov/health/topics/down

DS-Connect®: The Down Syndrome Registry

<https://dsconnect.nih.gov>

LuMind Research Down Syndrome Foundation

www.lumindfoundation.org

Other Alzheimer's Resources

Alzheimer's Association

www.alz.org

Alzheimer's Foundation of America

www.alzfdn.org



National Institute on Aging
National Institutes of Health
NIH... Turning Discovery Into Health®
U.S. Department of Health and Human Services



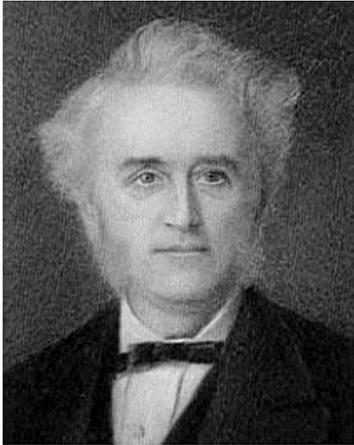
Down Syndrome –
Aging & Alzheimer's Disease Study



**Elizabeth Head & Frederick Schmitt
Sanders-Brown Center on Aging
University of Kentucky
Lexington, KY**

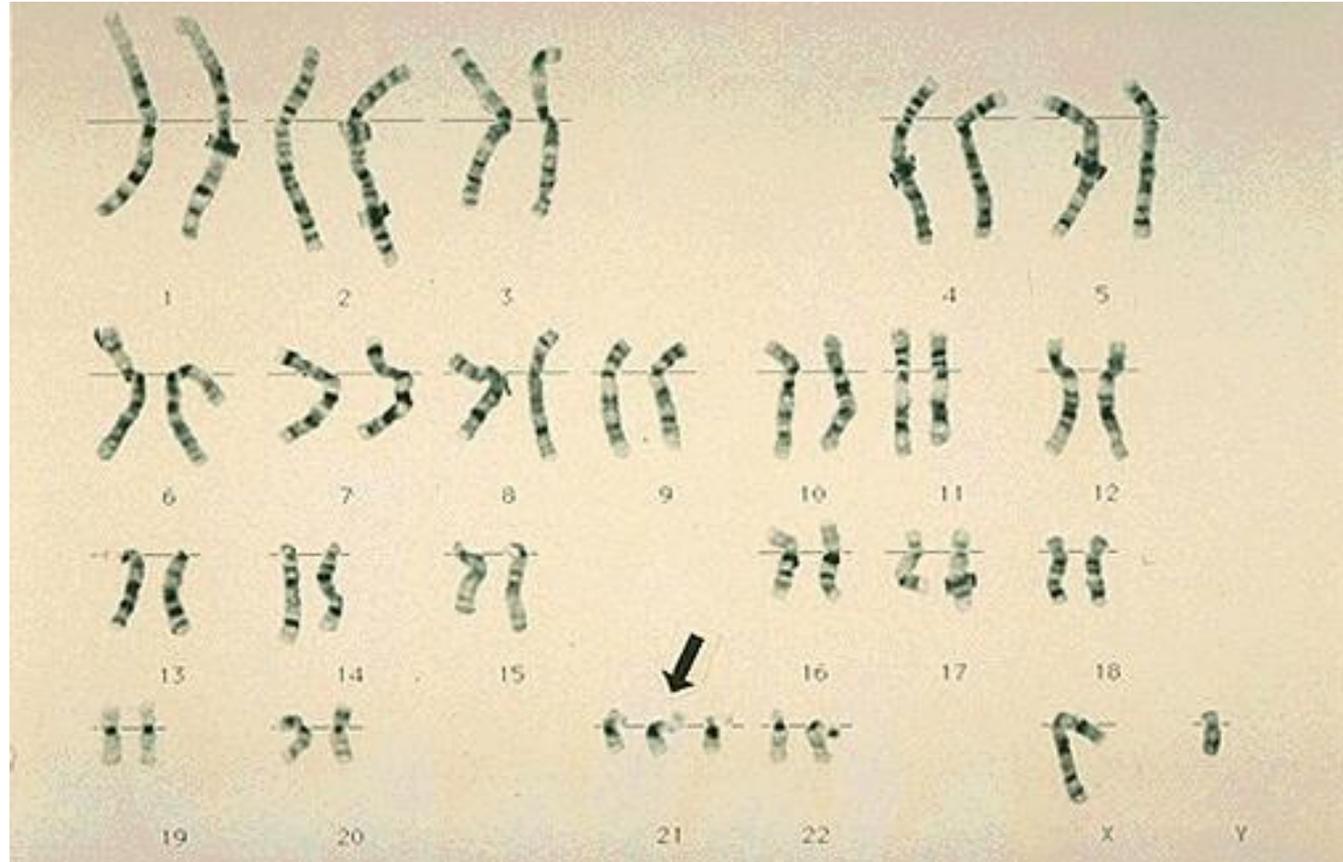
Funded by Department of Health and Human
Services, National Institutes of Health and the
Eunice Kennedy Shriver National Institute of Child
Health & Human Development

What causes Down syndrome?



J. Langdon
Down - 1887

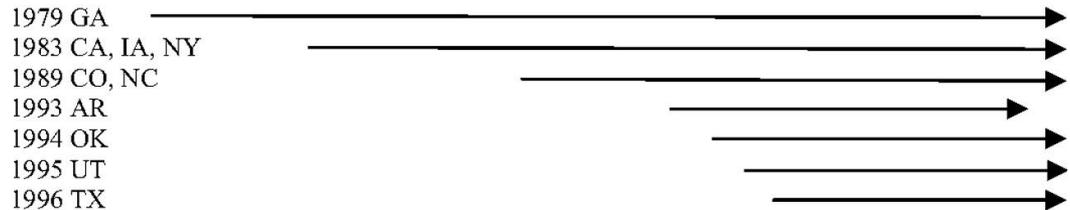
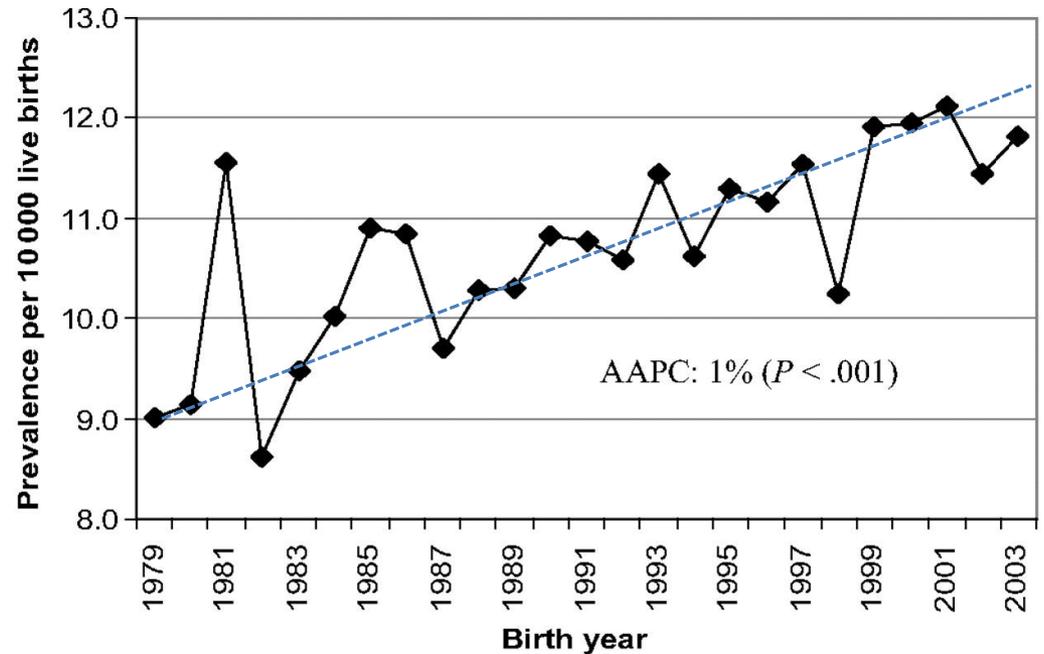
LeJeune, 1959



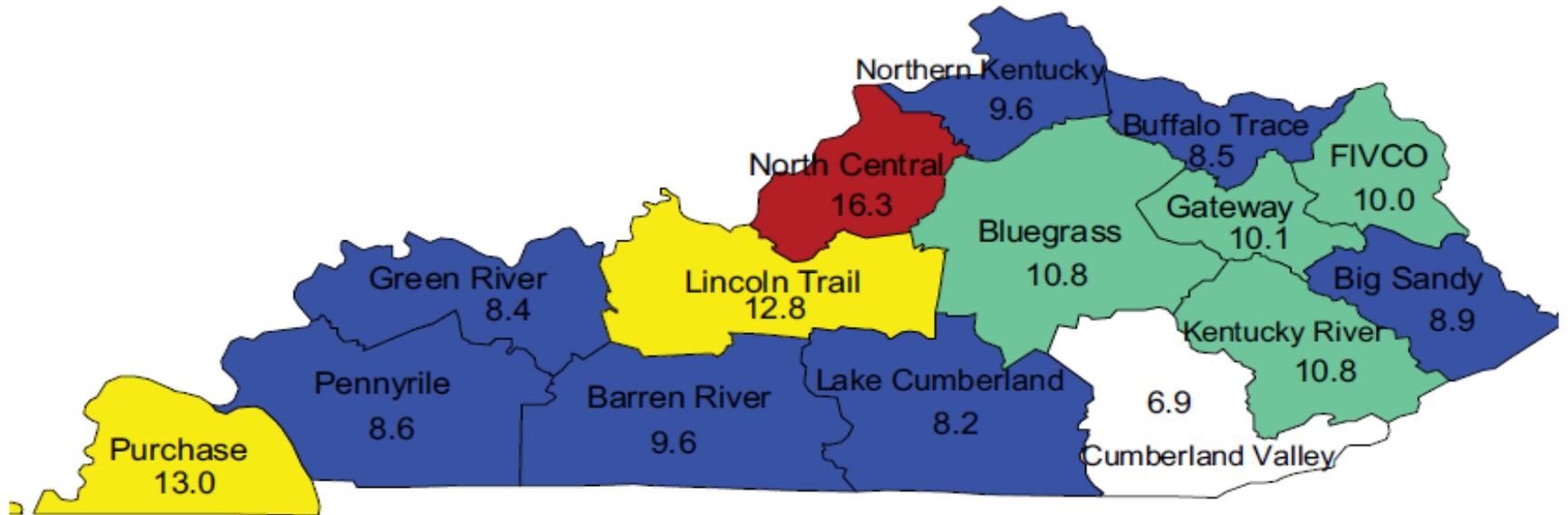
95% of people with Down syndrome have a full extra copy of chromosome 21
3-4% have a part of chromosome 21 triplicated
1-2% are mosaic

Overall prevalence of DS among live births in 10 US regions, 1979-2003

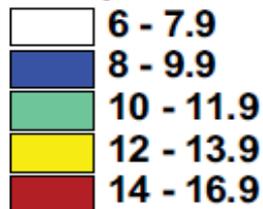
From 1979 through 2003, the prevalence of DS at birth increased by 31.1%, from 9.0 to 11.8 per 10,000 live births in 10 US regions. In 2002, the prevalence among children and adolescents (0–19 years old) was 10.3 per 10,000.



Rates* of Down Syndrome Among Kentucky Residents by Area Development District; 1998-2002



Rate per 10,000 births



*Rates are per 10,000 live births and fetal deaths

Cases are based on the ICD9 code 758.0

District is determined by the Mother's county of residence at time of birth

Source: Kentucky Birth Surveillance Registry, 1998-2002

Down syndrome (per 10,00 live births):

KENTUCKY

USA

Annual Cases

77

5,132

Prevalence

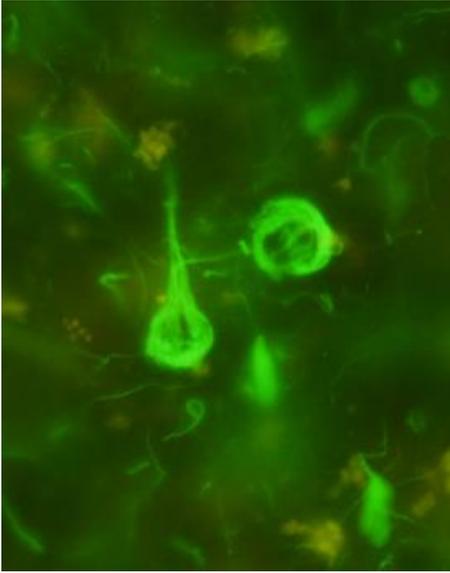
13.78

12.78

Adults with Down syndrome are at a higher risk for developing Alzheimer's disease than people in the general population

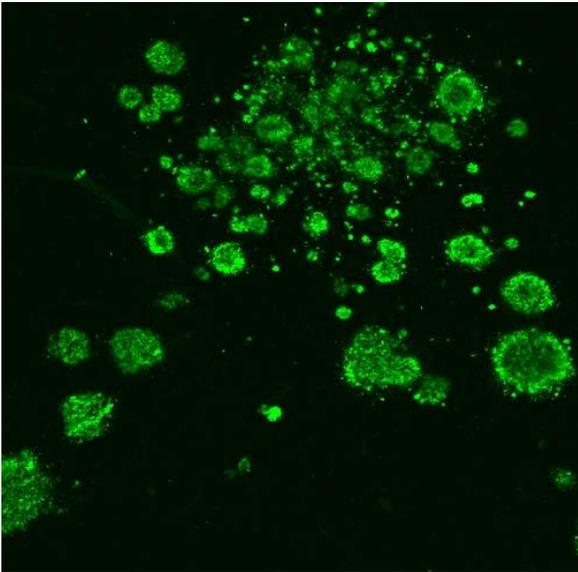
Why?

AD Neuropathology



Neurofibrillary Tangles

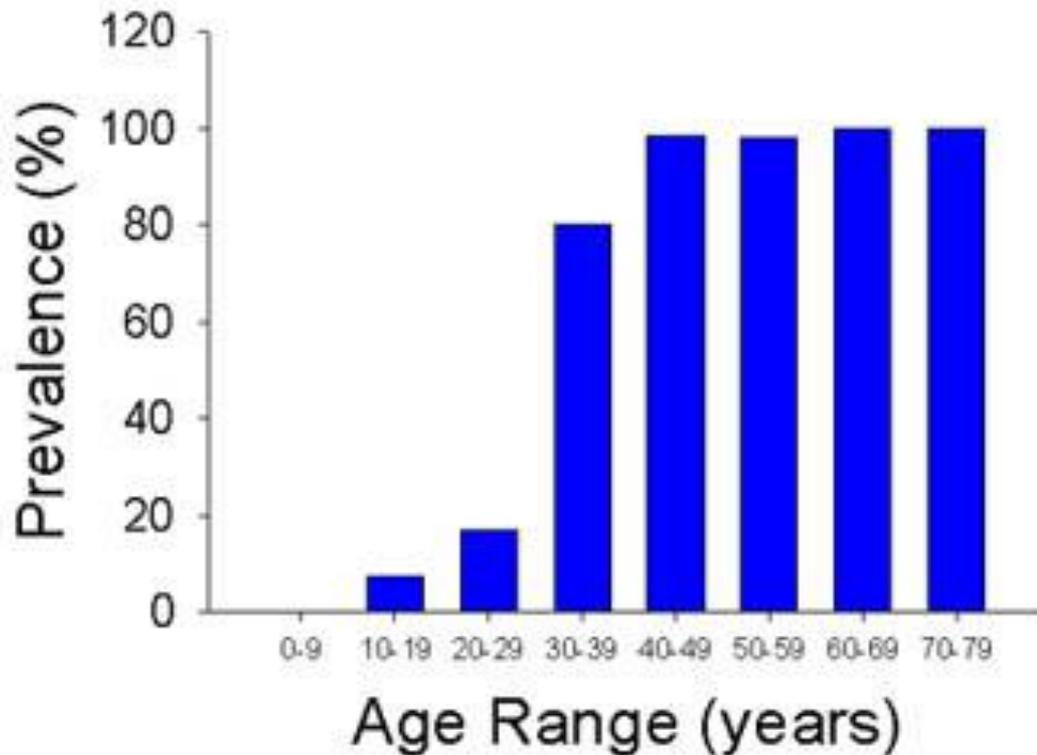
Made up of a protein called tau that collects inside of neurons and forms tangles. These tangles impair the ways neurons function and “talk” to each other



Senile Plaques

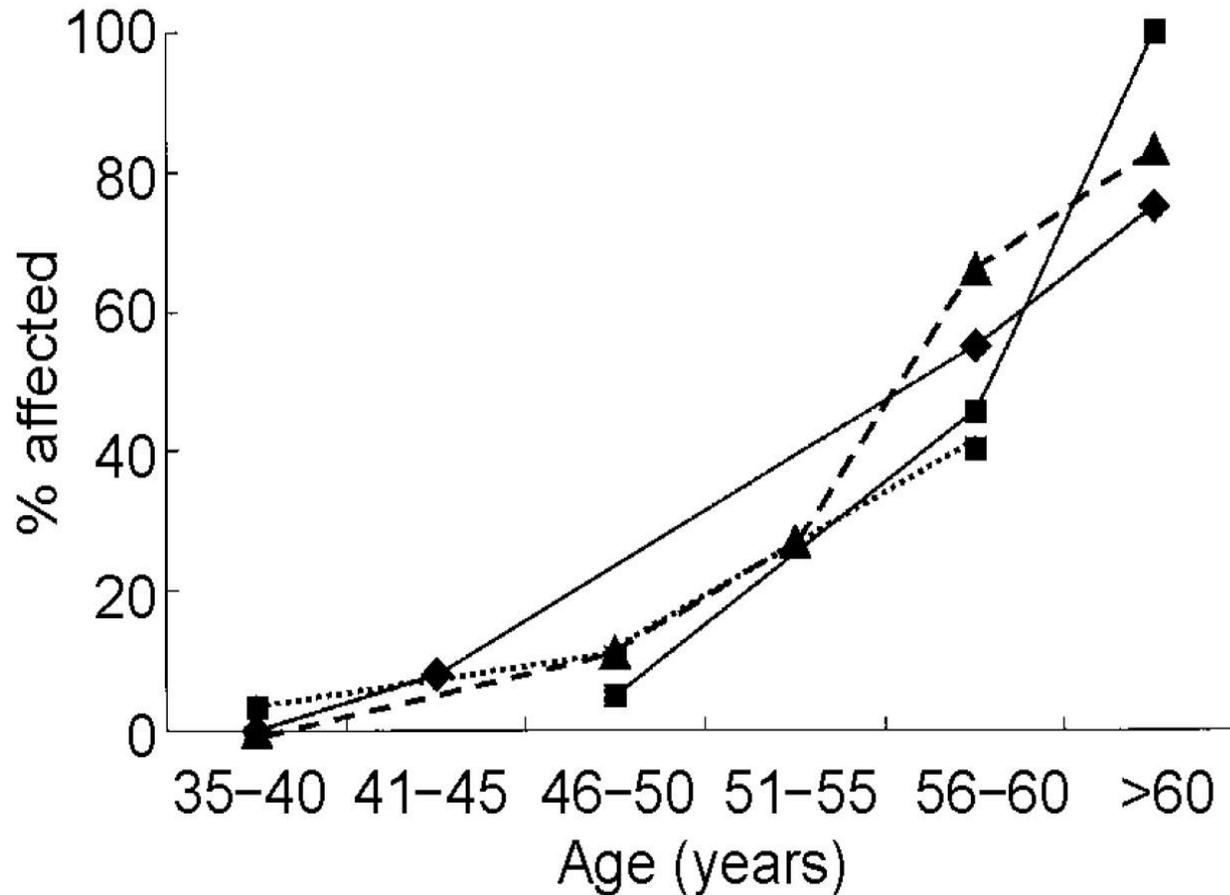
Made up of a protein called beta-amyloid that collects outside of neurons. The amyloid protein is toxic to neurons and makes them dysfunctional and may also kill them.

Virtually all adults with DS over the age of 40 years have sufficient **neuropathology** for AD



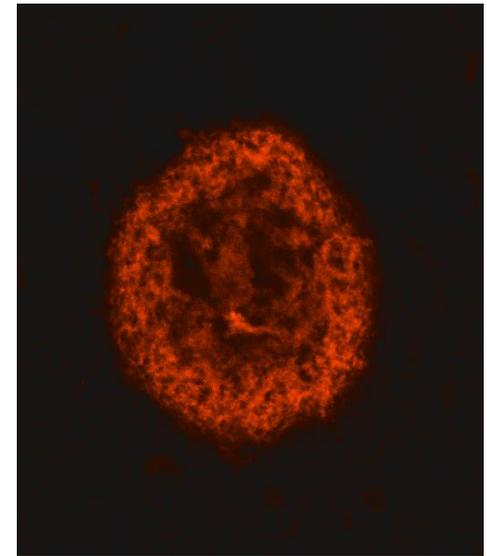
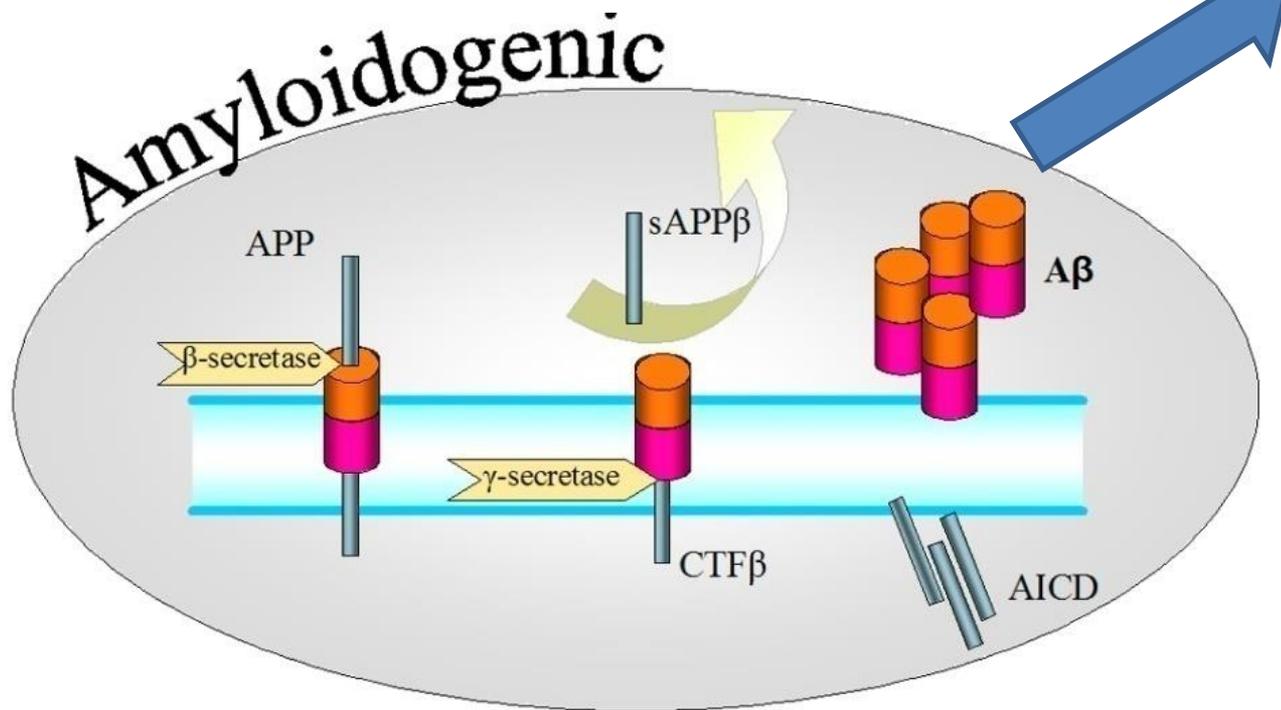
Mann et al., 1993

Number of people with Down syndrome and dementia



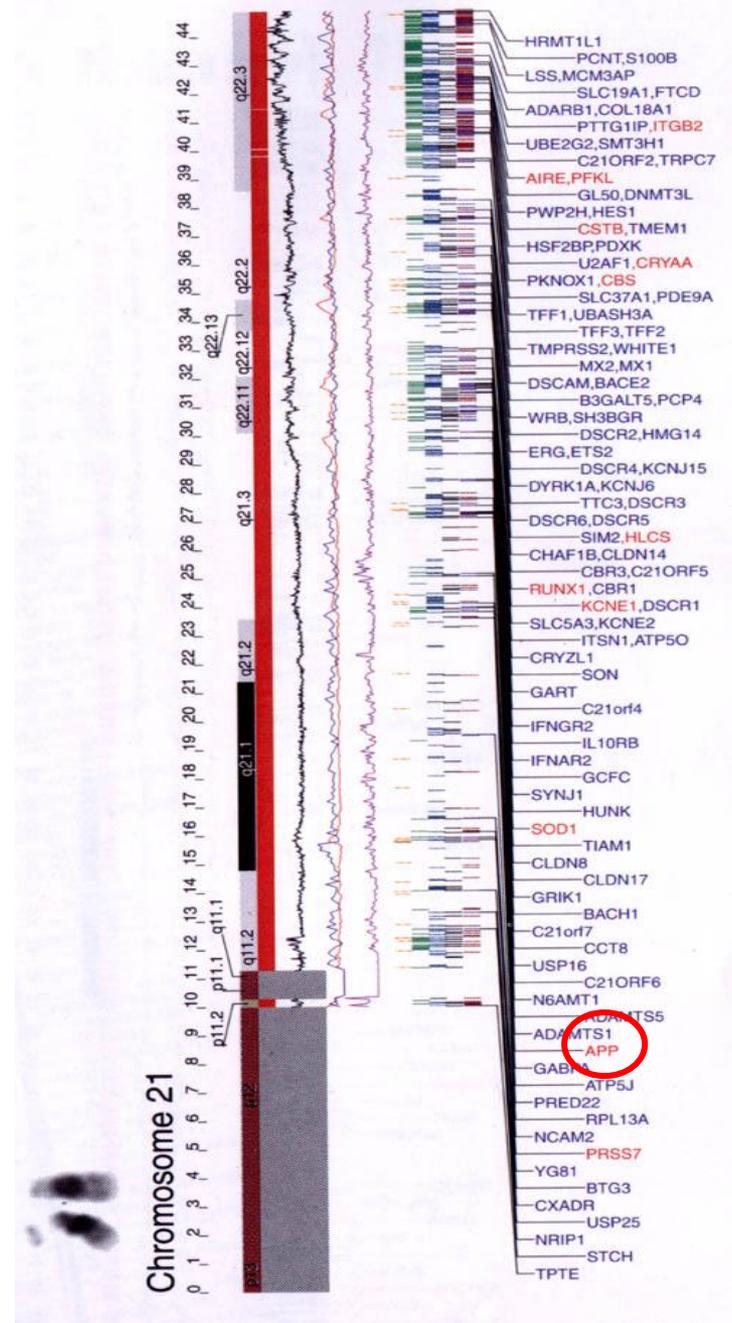
SCHUPF, N. et al. The British Journal of Psychiatry 2002;180:405-410

Where do senile plaques come from?



Amyloid precursor protein gene is on Chromosome 21

2001



Medical Conditions in DS

- **Seizures:** 7% in younger vs. 46% (age 50+)
 - possible link to myoclonus epilepsy gene on c21
 - possible dementia risk or prodrome?
- **Thyroid disease:** 35-40% DS adults
 - risk increases with advancing age (>GP)
- **Diabetes:** age of onset ~22 years for type 1
 - comparable to general population
 - Type 2 diabetes - preliminary report suggests a lower rate than general population
- **Obesity:** 45-79% of males; 56-96% of females are reported to be overweight

Percentages of Health Comorbidities in DS+AD

<u>Condition</u>	<u>AD+</u>	<u>AD-</u>	<u>ModAD</u>	<u>SevAD</u>
Epilepsy	56	12	39	84
Pulmonary	56	8	33	92
Poor Vision	89	72	85	92
Poor Hearing	44	21	46	44
Depression	38	18	49	16
Arthritis	14	2	21	8
GI Disorders	16	2	18	16

Note: persons with AD 55.4yo vs. w/o AD 50.8yo

Data adapted from McCarron et al., JIDR, 2005

Summary – aging in DS

- Individuals with DS are at high risk for AD with an earlier age of onset due to APP overexpression and early onset beta-amyloid accumulation
- Age-dependent brain changes involve beta-amyloid, then tangles, then dementia
- By studying tissue from individuals with varying ages we can learn what the earliest signs are of AD pathology
- We can identify appropriate ages for prevention or treatment clinical trials



The Down syndrome and Aging Study



The goal of this study is to follow people with Down syndrome over 25 years of age, who are not demented.

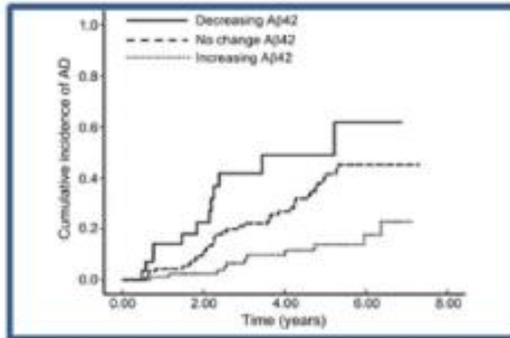
Every year:

- We measure **learning and memory**
- Participants have a medical exam by a **neurologist**
- We take **blood** samples for biomarkers and health
- We conducting **MR imaging** studies to look at white matter changes

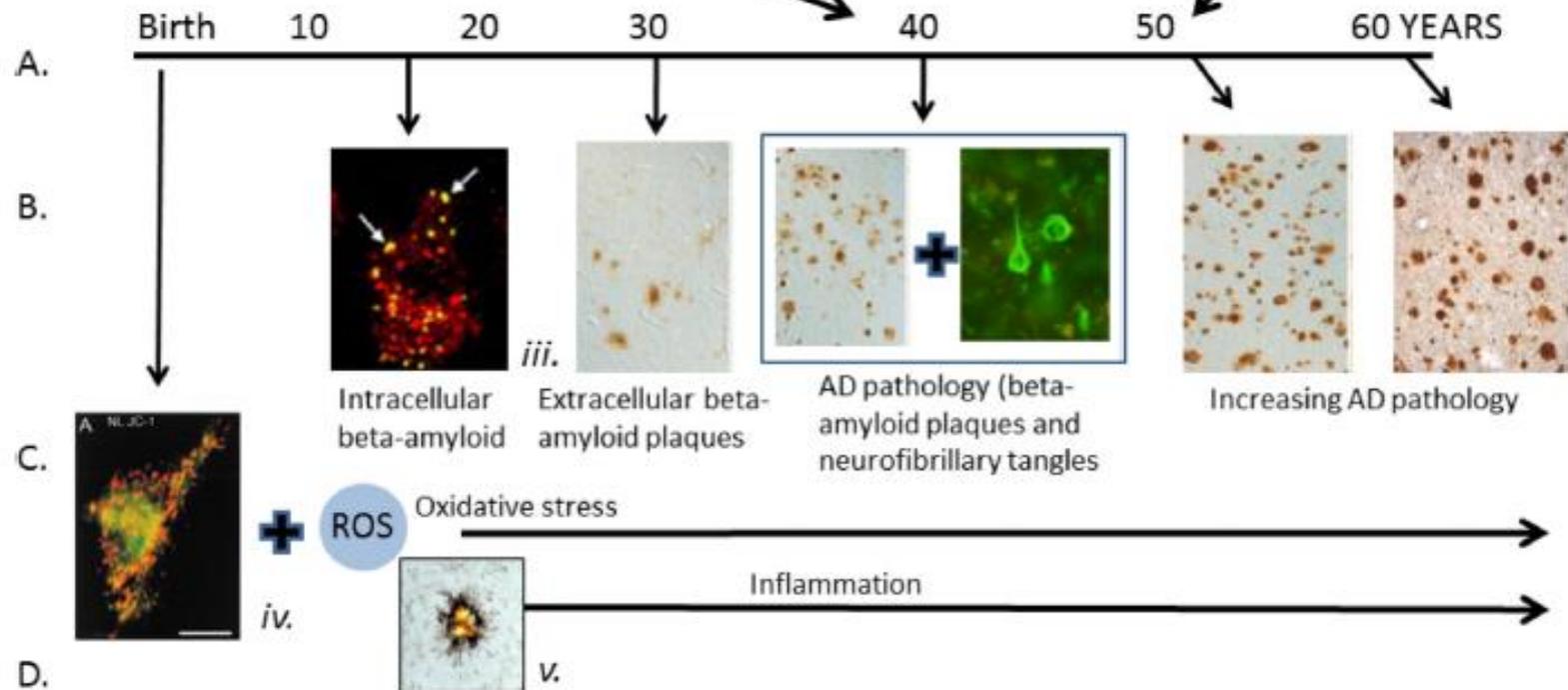
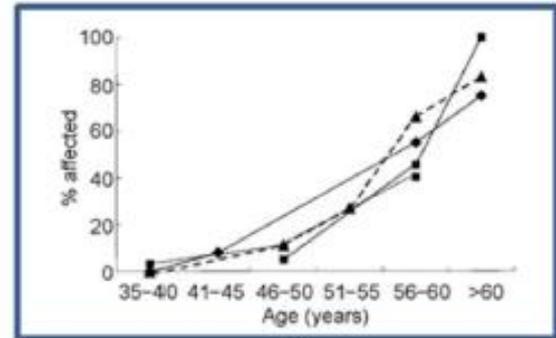


Aging in Down Syndrome Model

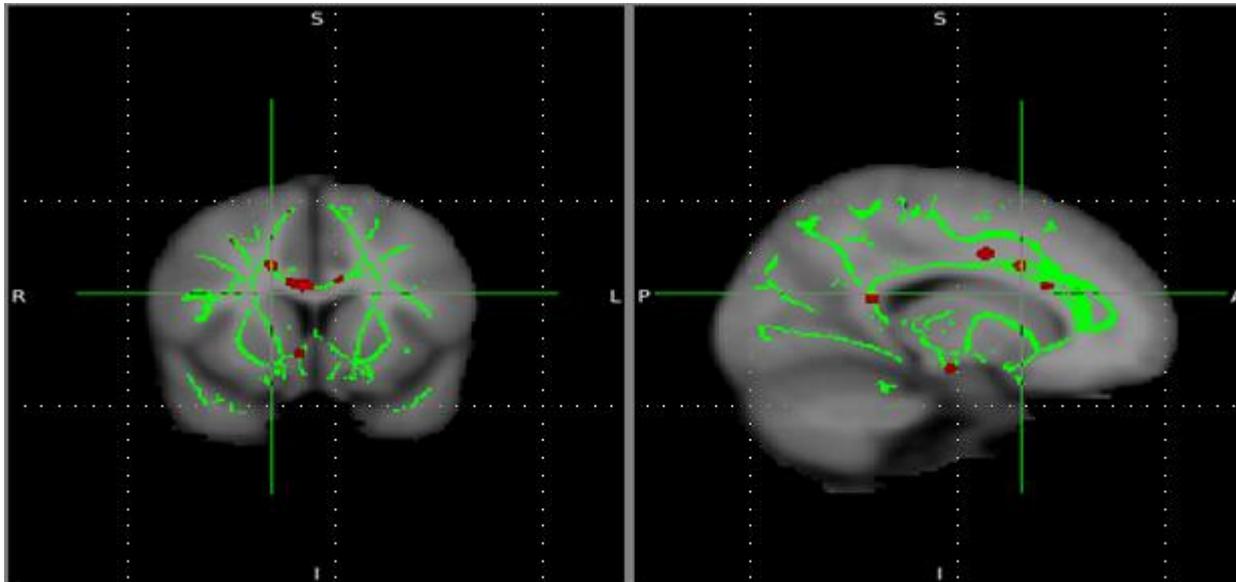
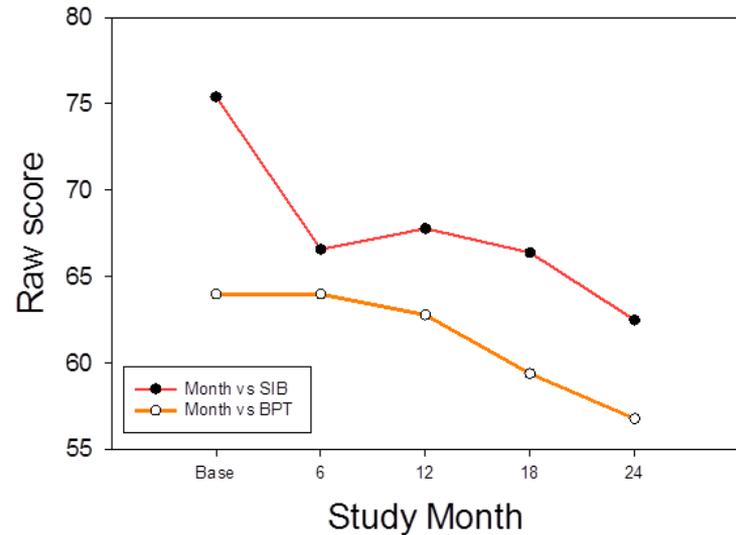
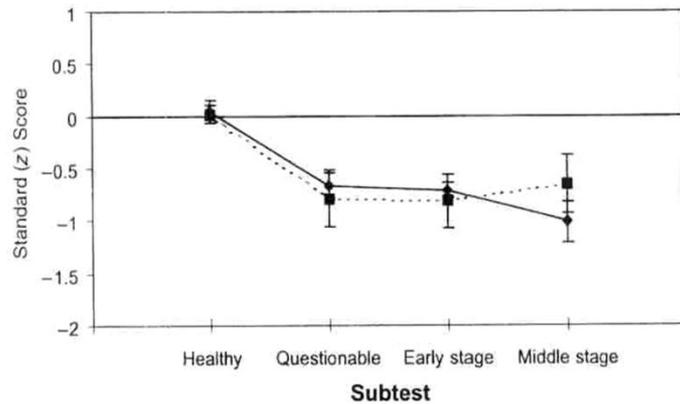
E. Plasma beta-amyloid



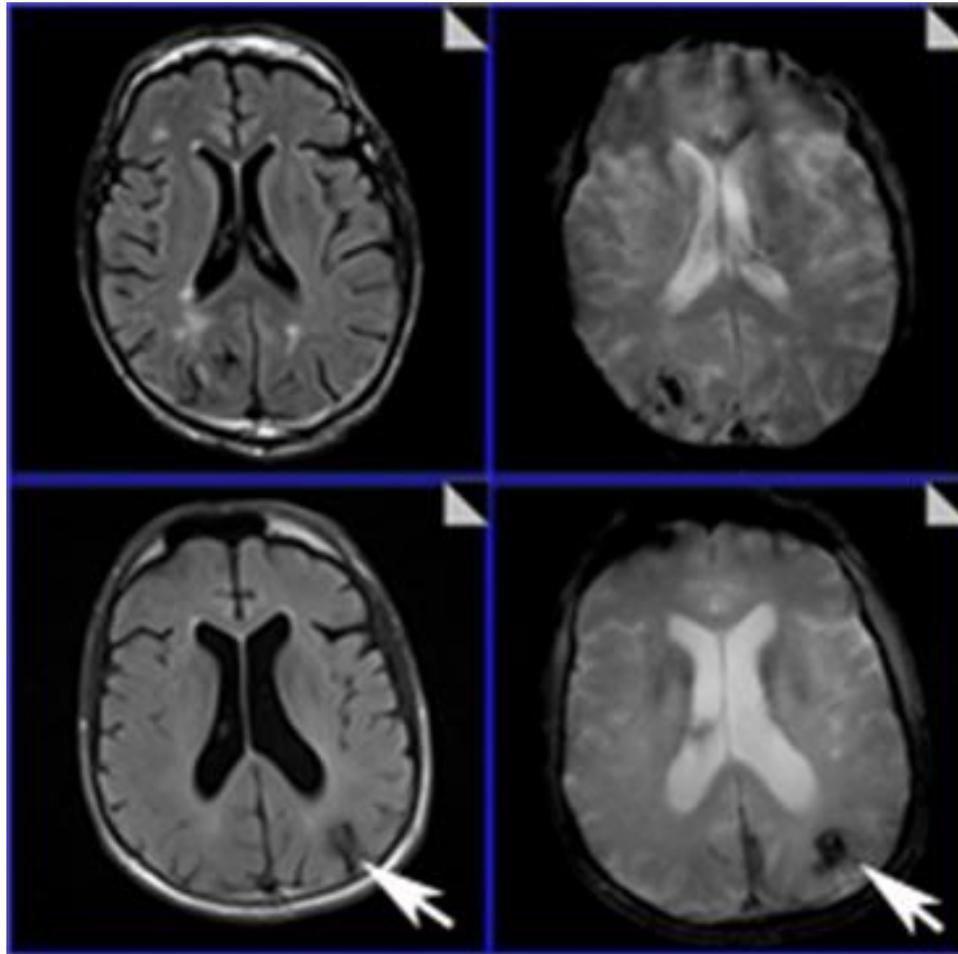
F. Clinical signs of dementia



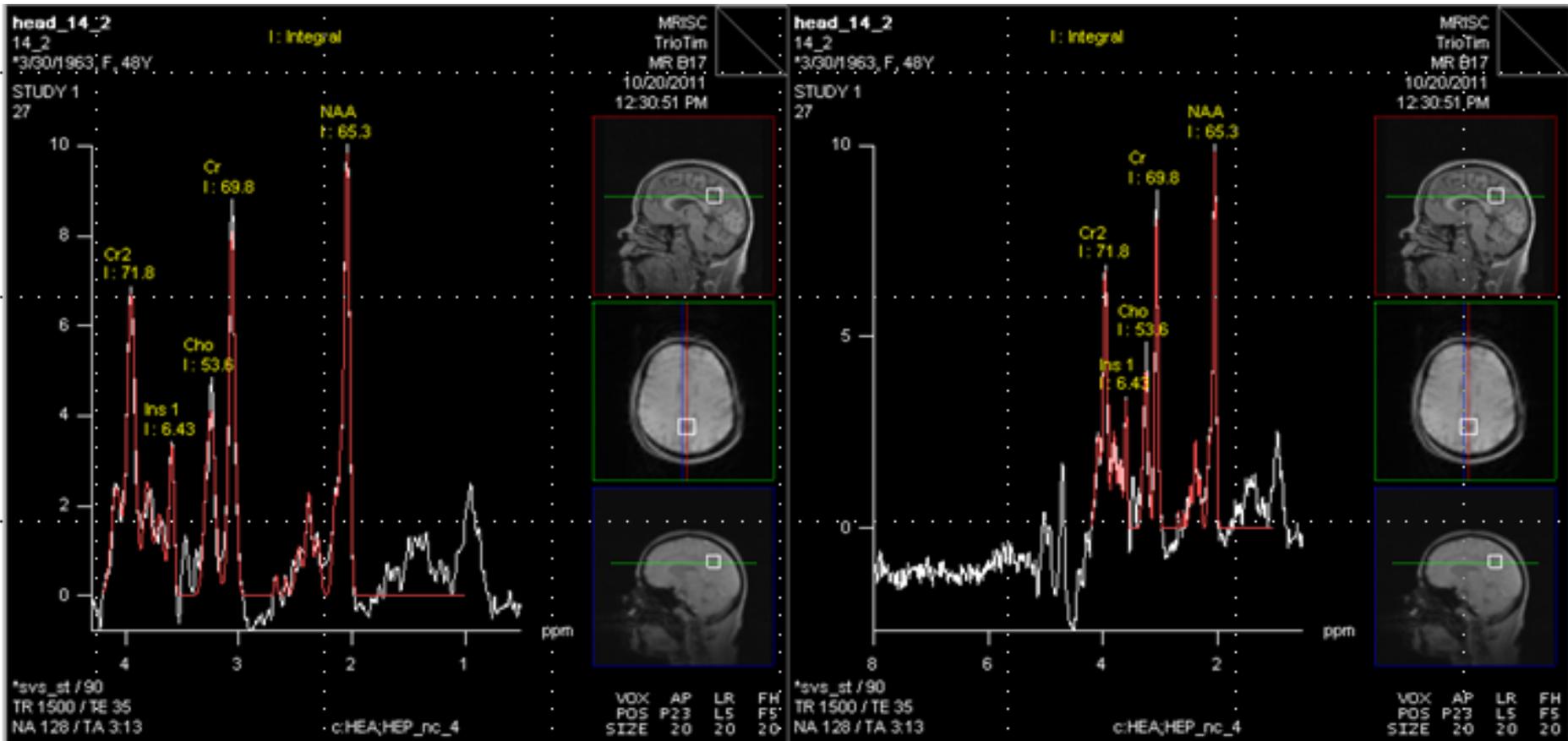
- Aim 1: continue to cognitively characterize a group of adults with DS and follow them for 5 to 10 years



- Aim 2: Detect cerebrovascular dysfunction (susceptibility weighted imaging, fluid attenuated inversion recovery & arterial spin labeling)



- Aim 3: Detect neuroinflammation
(magnetic resonance spectroscopy & blood biomarkers)

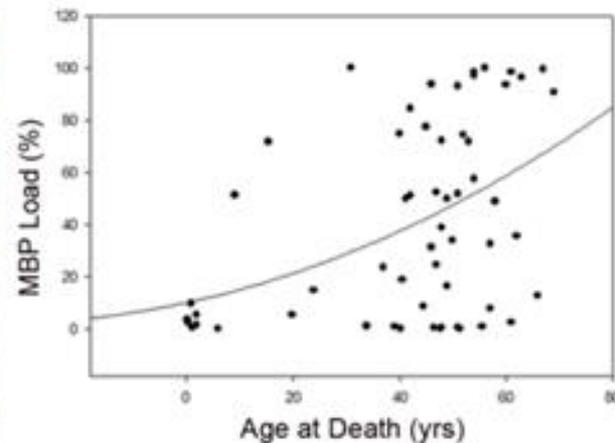


- Aim 4 measures proteins and RNA from brain tissue

A. MBP in Frontal Cortex



B. MBP increases with Age in DS



Myelin basic protein (MBP) immunolabeling increases with age and AD in DS at a similar age as our reports of decreased frontal WM integrity measured by DTI.



CONNECTIVITY, INFLAMMATION, AND CEREBROVASCULAR CONTRIBUTIONS

Why is this study important for not only people with Down syndrome but for everyone?



Not everyone with Down syndrome over age 40 has dementia.

By examining health, mentation, brain structure, and changes in other biomarkers (proteins) findings from this project could:

- Identify protective factors
- Lead to treatment strategies
- Inform prevention approaches
- Improve quality of life as people grow older

Our ADS Team



Dr. Robertson



Dr. Lightner



Dr. Powell



Dr. Gold



Dr. Jicha



Dr. Anderson-Mooney



'Main Study Team'

Many thanks! www.uky.edu/DSAging/



Down Syndrome – Aging & Alzheimer's Disease Study



Welcome

What's New!

Upcoming Seminars

What is the study about

What causes Down syndrome?

What happens in the study

Contact Us

Resources

Contact Information:

Roberta Davis
rdavi3@uky.edu

 859-257-1412  ext 479



Welcome!

Adults with Down syndrome are living long, productive, and healthy lives but face several challenges as they grow older. Although many people remain healthy, they are a vulnerable group of people who may develop Alzheimer's disease.

Alzheimer's disease is the most common form of dementia in our aging population and the earlier one is diagnosed, the better the possibilities are for symptomatic treatment of this disease. Currently, however, there are no cures for Alzheimer's disease.

Adults with Down syndrome are, unfortunately, at higher risk for developing Alzheimer's disease because most have an extra copy of chromosome 21. On this chromosome is a gene that is strongly linked to the development of Alzheimer's disease. **The good news is, not everyone with Down syndrome will develop dementia.**

The goal of our research is to follow people with Down syndrome as they get older. This will help us to understand why and who will develop dementia. Importantly, if we follow people who do not develop dementia we may be able to learn how to prevent this from occurring in others. The Down syndrome aging study is a new 5 year federally funded project taking place at the University of Kentucky that will allow us to follow adults with Down syndrome as they age to learn more about the challenges they might face.

The Down Syndrome Aging Study is a new 5 year federally funded project taking place at the University of Kentucky that will allow researchers to follow adults with Down syndrome as they age to learn more about the challenges they might face.

Dr. Elizabeth Head

Purpose of the study

This research seeks to understand how aging in Down syndrome may lead to Alzheimer's disease and affect a person's memory and thinking as they get older.

The goals of this longitudinal project are:

- * to follow neurological, learning and memory changes in adults with Down syndrome as they age;
- * to examine brain changes using MRI and;
- * to measure blood biomarkers.

In combination, the study hopes to identify early markers of the development of Alzheimer's disease in Down syndrome.



Sanders-Brown Center on Aging

800 South Limestone Street

Lexington, KY 40536

859-218-3865

<http://www.uky.edu/DSAging/>

Down Syndrome Facts:

- >More than 400,000 people in the United States have Down syndrome.
- >Down syndrome is the most commonly occurring chromosomal condition.
- >Life expectancy has increased dramatically from 25 years a generation ago to greater than 60 years today.
- >50% of people with Down syndrome age 55 and over may have Alzheimer's disease.

Alzheimer's Disease Facts:

- Alzheimer's is the 6th leading cause of death in the United States.
- 5.3 million people in the United States have Alzheimer's disease.
- Problems with memory and thinking are caused by loss of brain cells and are not part of normal aging.
- Studying the effects of Alzheimer's disease as people get older has allowed us to better understand the disease and begin to develop potential cures.

Aging and Down Syndrome Research Study



Who Can Join?

- Persons with Down syndrome age 25 and older with or without signs of Alzheimer's disease are eligible.
- Volunteers must be interested in participating in a five-year research study.
- You, a family member or caregiver will need to answer questions about your health.

For more information contact:

Roberta Davis

(859) 218-3865 or
rdavi3@uky.edu

<http://www.uky.edu/DSAging/>



Why Should I Join?

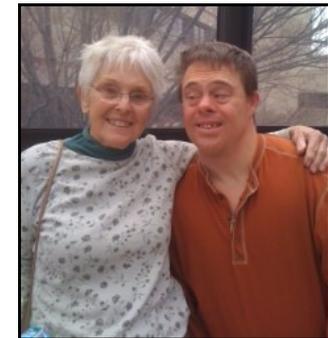
You can help us to better understand how memory and thinking change in persons with Down syndrome as they get older and why they are at a higher risk for Alzheimer's disease.

There will be no direct benefits to you from the research tests in this study. But, you may benefit from the medical examinations, blood tests and brain scans and they may show a disease or illness that needs further treatment. If we find a disease or illness, the study doctor will tell your guardian and your primary care doctor within 72 hours so that you can be treated.

Volunteers are being invited to take part in a research study involving 80-100 people with Down syndrome, which is being done as part of a study that is funded by the National Institutes of Health.

What will happen if I take part in the study?

-You will be scheduled for annual memory and thinking tests that can be done in a place convenient for you and your family.



-A yearly visit at the University of Kentucky for a general physical and neurological exam, complete blood tests to check you are in good general health, and a MRI (magnetic resonance imaging) brain scan. This visit will take about 3 hours, with breaks and snacks.

NOTICE:

CCDD SEEKS PUBLIC REVIEW AND COMMENT REGARDING NEW FIVE-YEAR STRATEGIC STATE PLAN



The Commonwealth Council on Developmental Disabilities (CCDD) is dedicated to creating systemic change in Kentucky that empowers individuals to achieve full citizenship and inclusion in the community through education, capacity building and advocacy. CCDD works through innovative programs, public policy and education to change systems that effective people with developmental disabilities.

CCDD's priorities are set forth in our Five-Year Strategic State Plan, which is developed based on a statewide needs assessment and comprehensive review of related data. CCDD is working to finalize a new Five-Year Strategic State Plan, which will be in effect from October 1, 2016 to September 30, 2021. It will be submitted to the Administration on Intellectual and Developmental Disabilities, our federal oversight agency, on or before August 15, 2016.

The Five-Year Strategic State Plan will establish Goals and Objectives related to the most pressing needs of Kentuckians with developmental disabilities and the mandates of the Developmental Disabilities Assistance and Bill of Rights Act. Based on these Goals & Objectives, we will develop strategies and action plans. Strategies may include initial funding for innovative programs, public policy advocacy, leadership development and collaboration. Please note, CCDD does not provide direct services.

Your Input Wanted

Public review of the Five-Year Strategic State Plan is required by law and helps us improve the plan. The public review period provides a 60-day window of opportunity for Kentuckians to evaluate the newly developed Goals and Objectives, and to share their comments so we can make improvements. We also welcome your suggestions for strategies and activities to help us achieve these goals and objectives. (Note: this is not a request for proposals, nor will suggestions be considered as formal proposals.)

Instructions

The Five-Year Strategic State Plan is available online at www.kyccdd.com. Other accessible formats of the document are available upon request. Please contact Carol Tudor carol.tudor@ky.gov or call (502) 564-7841.

Please submit written comments by email to carol.tudor@ky.gov. For each comment, please reference goal number and objective number.

Comment period:

March 1- May 1, 2016

Comments must be received via email by 5 p.m. EST on May 1st, 2016.

Thank you for your input!