

Making A Difference:

Avyllia's Hope

A Grandma's Dream Becomes a Reality



Pacific CIMAP

Pacific Consortium for Instructional Materials Accessibility Project

BACKGROUND

In October 2007, the University of Guam Center for Excellence in Developmental Disabilities Education, Research, and Service (Guam CEDDERS) received an Individuals with Disabilities Education Improvement Act (IDEA), Media & Technology Grant on behalf of the six Pacific entities of American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), the Federated States of Micronesia (FSM), Guam, the Republic of the Marshall Islands (RMI), and the Republic of Palau (ROP) to implement the Pacific Consortium for Instructional Materials Accessibility Project (Pacific CIMAP). The overall outcome of Pacific CIMAP was to implement and/or enhance each entity's system for providing timely educational materials in appropriate accessible formats for students with disabilities eligible for services under Part B of IDEA.

System improvement focused on supporting each entity to implement critical changes in policies, procedures, and practices related to meeting the IDEA National Instructional Materials Accessibility Standard (NIMAS) and facilitating the delivery of accessible formats (Braille, large print, audio, and digital) for children with print disabilities, including coordination with the National Instructional Materials Access Center (NIMAC) based on their eligibility under U.S. Copyright.

The IDEA refers to the U.S. Library of Congress definition of "print disabilities" within the 1931 Act to Provide Books for the Adult Blind for qualifying children with disabilities as having a print disability. This definition includes children who are blind, have low vision, have physical disabilities, or have reading disabilities that prevent their ability to read using standard printed materials. These children with print disabilities would therefore require

the use of educational materials in appropriate accessible formats to progress in their educational program.

The resources provided through Pacific CIMAP ended in December 2009. However, in the short 27 months of implementing Pacific CIMAP, the Pacific entities have shown significant system improvement through infrastructure development in policies, procedures, and practices, including being exposed to and having available state-of-the-art technology for accessing and creating educational materials in accessible formats.

Guam CEDDERS is proud to present "Making a Difference: Avyllia's Hope," a supplement to the March 2010 *I Tellai* Quarterly Newsletter, as an example of the system improvement supported by Pacific CIMAP. This short *I Tellai* addition highlights the results from implementing Pacific CIMAP through the island-way of storytelling. Along with photos that are "worth a thousand words," Avyllia's story is an example of Pacific CIMAP's positive impact on the efforts put forth to improve educational services for children with print disabilities. Avyllia's story is about one family's experience with "possibilities" that, in many respects, represents the desire of other families who want the "possibilities" to be available and accessible on their islands. This

I Tellai supplement also features a timeline of major activities conducted by Pacific CIMAP.

Guam CEDDERS will be publishing a Final Outcomes Report that incorporates this supplement and other island stories of how Pacific CIMAP has made a difference for children with print disabilities in their entity's system, which expands the results reported in the February 2009 *Pacific CIMAP Outcomes Report: Making a Difference for All!*

PACIFIC CIMAP STAFF

Heidi San Nicolas, Ph.D.
Principal Investigator

June De Leon
Project Director

Asuncion (Connie) Guerrero
Project Coordinator

Mary Kidd
Training Associate

Joseph John (JJ) Mendiola
Data Coordinator

Jonas Macapinlac
Media Specialist

Dolores (Dee) Palomo
AT Assistant

For more information, contact:
June De Leon
at (671) 735-2494 or email at
june.deleon@guamcedders.org



Two years ago, Justina asked, “Is there hope for my granddaughter, Avyllia?” Justina’s hope for Avyllia was to see people work together to bring appropriate services to the islands. Her hope was for an educational system that connects at all levels to make things happen for children in the islands. Today, Justina says that she can see Avyllia’s hope in Roddy, Karlina, Arthur, and June. Her dream has become a reality.

When Avyllia was 10 months old, she lost her ability to see and underwent surgery to alleviate the pressure around her brain. In addition to losing her vision, Avyllia had difficulty with physical balance and walking. At that time, family and friends encouraged Justina to take Avyllia off-island so that she could get better services, such as equipment and specialists. But Justina knew that she didn’t want to take Avyllia away from their large family in Pohnpei. And if Avyllia was to leave, Justina knew that she wouldn’t be able to go with her to live away from home. Justina wanted Avyllia to stay in

Pohnpei with family and hoped for services, maybe not all the services like in the U.S. mainland, but at least some of the services to be available in Pohnpei. Justina said, “Why can’t we bring what we need to Pohnpei instead of living off-island to get what we need? We want to have at least some of what they have, not only for Avyllia, but for the other kids who need it so that they can grow up and be independent. I know we can have what they have there.”

“Why can’t we bring what we need to Pohnpei instead of living off-island to get what we need?”

Today, Avyllia is 4 years old and lives with Justina Olter (grandma), Wilson Olter (grandpa), Jo Ann Olter (mom), and Koropin David, Jr. (dad) at home in Pohnpei, one of the four states of the Federated States of Micronesia (FSM) in the Western Pacific region. She is a beautiful, bright, and very outgoing young girl who tells you what’s on her mind.

Justina describes Avyllia as a very courageous and demanding child. Avyllia knows what she wants and is not afraid of doing things, even though she still has some problems with walking on rough or uneven surfaces. One time, a person was talking about feeling sorry for Avyllia

continued on page 6 ►

Pacific CIMAP

Pacific Consortium for Instructional Materials Accessibility Project

Timeline

TIMELINE of major Pacific CIMAP activities implemented from October 2007 through December 2009 with the six Pacific entities that include nine island communities: American Samoa, CNMI, FSM (Chuuk, Kosrae, Pohnpei, and Yap), Guam, RMI, and ROP.

Oct '07



Guam CEDDERS was awarded a grant from the U.S. Department of Education, Office of Special Education Programs (OSEP) to administer **Pacific CIMAP**.

Jan '08

Pacific CIMAP Updates, a presentation at the NIMAS Implementation Council Meeting, Orlando, Florida.

Feb '08

On-site visit to Pohnpei and Chuuk with Donna McNear, Lead Consultant, and Jim Fruchterman, CEO, Benetech Initiative/Bookshare.



Feb '08

Regional Leadership Meeting I held at the University of Guam with 30 key leadership personnel from all 9 island communities. The meeting included a review of the NIMAS/NIMAC requirements and the results of the needs assessment completed for each island community.

Jul '08

NIMAS and Beyond in the Pacific, a presentation at the OSEP Project Directors' Conference, Washington, D.C.

Jul - Aug '08

Crafting and Transforming Accessible Materials, the Summer 2008 Regional Institute held on Guam for 47 Jurisdiction Implementation Team (JIT) members from all 9 island communities. The intensive institute provided specific training on software, tools, and equipment, purchased for each island community, designed to access, produce, and apply technology for crafting and transforming educational materials into appropriate accessible formats, as well as training on the online data management system.



Jan '09

Pacific CIMAP Updates, a presentation at the NIMAS Implementation Council Meeting, Orlando, Florida.

Feb '09

Regional Leadership Meeting II, at the University of Guam with 44 key leadership personnel, including 9 Chief State School Officers from the island communities. The meeting included a review of the status of each entity's policy, procedures, and practices in relation to the NIMAS and NIMAC requirements. The February 2009 Pacific CIMAP Outcomes Report: Making a Difference for ALL! was disseminated at the meeting.



Oct '09

Making a Difference for ALL!, a presentation at the NIMAS Related projects Meeting and AIM Consortium Meeting, Washington, D.C.

Oct '07 - Jan '08

On-site visit to all 9 island communities to complete needs assessment of **IDEA NIMAS/NIMAC** requirements.

Nov '07

Meeting held in Washington, D.C. with Pacific CIMAP collaborators and federal officials.



Feb - Jul '08

All 9 island communities register with **Bookshare.org**, an Accessible Media Producer (AMP).



May '08

Making a Difference for ALL!, a presentation at the NIMAS Related Projects Meeting, Washington, D.C.

Aug '08

State Response to the National Instructional Materials Standard (NIMAS): An Opportunity, a presentation at the OSEP Leadership Conference, Baltimore, MD.



Sep - Dec '08

On-site visit to all 9 island communities to address the policy, standard operating procedures, equipment usage, and data management, including a visit with Donna McNear, Lead Consultant, to Pohnpei, Yap, CNMI, and Guam.



May '09

Pacific CIMAP & Bookshare.org: A Partnership for Crafting and Transforming Accessible Formats In the Pacific, a presentation at the PacRim Conference, Honolulu, HI.

Jul '09

Summer 2009 Braille Training held in Pohnpei, FSM, in conjunction with the FSM Micronesia Teacher Education Conference (MTEC). The training included 38 entity JIT members and personnel working with children who are blind, and focused on Braille/tactile formats.



Aug - Dec '09

On-site visit to all 9 island communities to support the implementation of the policy, procedures, and practices for providing timely educational materials in appropriate accessible formats, including a visit with Donna McNear, Lead Consultant, to American Samoa, Guam, CNMI, Chuuk, RMI, and ROP.

Dec '09

Regional Low Vision Training held at the University of Guam with 40 JIT members and personnel working with children with low vision. The training focused on the use of low vision technology, purchased for each island community.





September 2008: Avyllia hesitatingly tries to use the Mountbatten Brailier for the first time with assistance from Justina (*Left*) and Roddy (*Center*) at the Pohnpei State CIMAP Resource Center.



July 2009: (*Right*) Avyllia claps in celebration after demonstrating how to use the Mountbatten Brailier, her “computer,” during the Pacific CIMAP Regional Braille Training held in Pohnpei State, FSM.



Avyllia and her father share a laugh.

because something was wrong with her eyes. Avyllia, listening nearby, quickly corrected that person by saying “there is nothing wrong with my eyes.” Avyllia’s family encourages Avyllia to do things, even sometimes to the point where Justina admits that they might be spoiling her because they let her do what she wants-most of the time. Justina knows that Avyllia can learn and do things for herself.

Avyllia might have lost her ability to see with her eyes, but she definitely can see through her adventurous personality nurtured by the love and encouragement of family and friends. Avyllia enjoys singing, being with family, and going to the family store where her mom works. When she grows up, Avyllia says that she wants to work at the store.

Justina knows that Avyllia will soon be going to the early childhood education program at an elementary school. Her concern for Avyllia going to school is not about Avyllia herself, but for the other kids. Justina is concerned that Avyllia would be a distraction to the other kids. She says that Avyllia can be “very persistent in her wants and needs,” which might take away learning time from the other kids. To assist with Avyllia’s transition from home to school, Justina is looking forward to observing the early childhood classroom to see what needs to happen now so that Avyllia will be comfortable with the environment, and with careful



Teacher Roddy works with Avyllia on using flashcards with Braille letters for identifying sounds.

planning, will not interrupt any child’s learning. For Avyllia, she says, “I’m going to school by myself and not with grandma.”

The Educational System: Connecting at All Levels to Make Things Happen

Avyllia’s hope in Roddy. Today, Avyllia receives home services from the Pohnpei State Special Education Program. She is learning pre-literacy skills using Braille through a variety of instructional methods and tools. Roddy Robert, Itinerant Vision Specialist for Pohnpei State Special Education Program, describes Avyllia as a fast learner and a wonderful little girl who knows what she wants. “Teacher Roddy,” as Avyllia calls him, makes weekly home visits with Avyllia and Justina. The visits include working on storytelling, reading, and learning Braille to read and write through the use of flash cards, story books, and the Mountbatten Brailier.

The Mountbatten Brailier is a complete Braille learning system for children from the early stages of Braille instruction to advance use of the system through high school and beyond. Distributed by HumanWare U.S., Quantum Technology developed the Mountbatten Brailier on the premise that “literacy is basic to all learning, and learning is fundamental to every child’s success. Literacy through Braille opens new pathways of communication and expression, addressing needs that cannot be fulfilled by verbal and audio methods.” (<http://www.mountbattenbrailier.com/support/resources.htm#mountbattenuserman>)

Teacher Roddy shared that when the Mountbatten Brailier was introduced to Avyllia, she was scared of using it, but now she is very comfortable with the equipment functions and even calls it her “computer.” During a recent visit, Teacher Roddy reviewed the use of the Mountbatten Brailier with Justina. Justina said that she would like to learn how to teach Avyllia so that her family can continue teaching Avyllia when Teacher Roddy is not there. Teacher Roddy expressed that services have changed a lot when they



Justina said that she would like to learn how to teach Avyllia so that her family could continue teaching Avyllia when Teacher Roddy is not there.

started to work with parents and children who are blind with the equipment and tools, such as the Mountbatten Braille, provided through the Guam CEDDERS Pacific CIMAP, based at the University of Guam.

Pacific CIMAP facilitated regional training sessions on the use of the equipment and tools, but more importantly, provided the equipment and tools to take back home to the islands for immediate use. This allowed each entity to immediately apply what they learned in the training sessions. In addition to the Mountbatten Braille, equipment and tools were provided for the production of printed materials in Braille and large print, as well as to access audio and digital formats of the printed materials.

Avyllia's hope in Karlina. Karlina Henry is the Acting Coordinator for the Pohnpei State Special Education Program. She is responsible for administering and supervising special education services for children with disabilities in Pohnpei State. Karlina is very familiar with Avyllia's educational needs having met with Avyllia, Justina, and Jo Ann two years ago. Karlina has been working to ensure that Pohnpei State develops a system for providing educational materials in accessible formats, such as Braille, large print, audio, and digital, for students with print disabilities, including appropriate storybooks for Avyllia. The Mountbatten Braille was one of the "advanced technologies" brought to Pohnpei through the Guam CEDDERS Pacific CIMAP. Karlina shared that she has seen how technology can work in the islands for children with disabilities. Of course, she understands that they need to purchase more of the equipment and tools for the students. But, in relation to the use of advanced technologies, Karlina states, "I am sure that our students can get caught up with

other students out there who have been using this type of equipment, and I can see now that there is hope for them to compete in the world in going to college."

Avyllia's hope in Arthur. Arthur Albert is the Chief of the Special Services Division, FSM National Department of Education. Arthur serves as the Executive Director of the FSM Special Education Program responsible for the general supervision and monitoring of special education and related services for children with disabilities in all four FSM States: Chuuk, Kosrae, Pohnpei, and Yap. With the FSM Secretary of Education serving as the grantee for the U.S. IDEA Part B funds, Arthur monitors the distribution and use of the IDEA Part B funds in each FSM State. He also facilitates additional technical assistance and resources for FSM in support of improving special education services provided for close to 1,700 children with disabilities in the FSM.

Two years ago, Arthur met Justina and shared that the FSM was a partner in a U.S. federally-funded project designed to bring the technical assistance and resources to the FSM to strengthen special education services provided for children with print disabilities, including Avyllia. This certainly sparked an interest in Justina because the hope that she was looking for in bringing resources to Pohnpei was what she was asking about, and now, it seemed like it was happening. Her dream was becoming a reality.

Avyllia's hope in June. June De Leon, Guam CEDDERS Associate Director, has served as the Pacific CIMAP Project Director responsible for the implementation of project activities to meet the established objectives, goals, and overall outcome of supporting the

continued on page 8 ►



Mom, Avyllia, and Dad read a story together.

implementation and/or enhancement of each entity's system for providing timely educational materials in appropriate accessible formats for students with disabilities who are eligible for services under Part B of IDEA.

During a 2008 on-site follow-up visit to Pohnpei, Arthur mentioned his meeting with Justina who also serves on the Pohnpei State Special Education Advisory Panel. Arthur expressed how important Pacific CIMAP is to the children in FSM, including Avyllia, especially in bringing the resources to the islands-the state-of-the art technology – equipment, tools, software – to support the production and distribution of appropriate educational materials in accessible formats, including locally developed educational materials in the indigenous languages.

During that visit, June met with Justina, Avyllia, and Jo Ann to show them the technology purchased by the project and to share how the project has provided intensive training to local personnel on how to use the equipment and tools.

Recently, June was able to visit with Avyllia and her family once again-two years later. She was able to “talk story” with Justina, Avyllia, Jo Ann, and David, but more importantly, was able to see how the Mountbatten Braille and other strategies were being implemented for developing Avyllia's and her family's Braille literacy skills. This was definite evidence of how partnerships with educational systems, consultants, and trainers, especially with the guidance from lead project consultant, Donna McNear,

can result in realizing the positive impact of technology in special education for children with print disabilities in the islands.

Partnership with Families: The System that Makes Things Happen

Grandma's Dream Becomes a Reality. Today, Justina says she can see Avyllia's hope in Roddy, Karlina, Arthur, and June-people working together to make things happen. These individuals represent the various aspects of an educational system working with the child and family, from the direct service provider/teacher, to the administrators, to a collaborative partner for technical support. Avyllia's hope is an example of how partnership between the educational system and families is truly the system that makes things happen.

Today, with support from Pacific CIMAP, Avyllia's hope is a reality that can be seen in ALL Pacific island communities. Being able to bring the resources, technology, and training to the region and to each island community ensures that the “possibilities” will have meaningful application on each island.

On behalf of Pacific CIMAP, **Kalahngan** (Thank You) Justina for holding on to family and for having the passion, commitment, and trust in “working together” with Roddy, Karlina, Arthur, and June to bring what's important to the families and children in Pohnpei!!