



## Iowa’s Deafblind Services Project – Deafblind Registry Fact Sheet

Why is it important for children to be identified for the Iowa Deafblind Registry?

- The earlier that we identify children, the more quickly the family and team can consider programming that focuses on the unique needs of a child with a dual sensory impairment.
- Even if the parents do not want to participate in any Project services, the educational team will have access to technical assistance and be given preference when registering for Project professional development opportunities to increase their skills and knowledge when working with children with deafblindness.
- The Project does sponsor parents to attend Deafblind specific workshops and conferences in Iowa and the US.
- Federal funding to continue providing services to children with deafblindness is dependent upon the number of children we have identified.

What can I tell parents about the Deafblind Registry?

- Information is confidential and only reported out to the National Deafblind Consortium per agreement with the Federal government.
- A child’s name can be removed from the Registry in the future if there is a change in vision or hearing status.
- Parents have access to Project staff that can provide technical assistance and consultation in the home, school and community settings.
- The Deafblind Project may send out emails or information such as newsletters or workshop brochures, but the Project will never contact a family for other reasons.

Is my student eligible for the Registry?

- A child does not have to be totally blind or totally deaf to be considered Deafblind.
- There are many syndromes associated with deafblindness including the following (this is only a partial list – please refer to the Deafblind Project website for additional information).

<b>Hereditary/Chromosomal Syndromes</b>	<b>Pre-Natal/Congenital Complications</b>	<b>Post-natal/Non-congenital Complications</b>
CHARGE Association	Congenital Rubella	Asphyxia
Cornelia DeLange Syndrome	Cytomegalovirus (CMV)	Meningitis
Down Syndrome	Fetal Alcohol Syndrome	Severe Head Injury
Leber congenital amaurosis	Maternal Drug Use	Stroke

For more information, please contact the Project webpage [www.iowadeafblind.org](http://www.iowadeafblind.org) or:

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